

BY DAVINA GORDON

On April 23, Steve Moore (42) was among the 40,000 competitors who ran the Virgin London marathon. While many run to achieve personal and fitness goals, Steve was one of those running for an important cause. His young cousin Hannah Gillespie (11) suffers from Fanconi Anaemia, a rare, life-limiting genetic disorder which causes bone marrow failure in children and a predisposition to gynaecological and head and neck cancer. Hannah was born without thumbs and with small hands that stuck out at right angles on her forearms. She also had four holes in her heart, only one kidney and dislocated hips and was deaf.

"Hannah is an inspiration. If you think you're having a tough day, you think about how much she has been through and it puts things into perspective."

Steve was in the Royal Victoria Hospital for the birth of his son Ryan at the same time Hannah was born. "It was a joyous family occasion."

The London marathon wasn't his first rodeo, having run the Dublin marathon in 2001 in, he laughs, "a shamefully slow" time of five hours and five minutes.

The father-of-three certainly upped his game with a very respectable finishing time of three hours and 58 minutes while his wife Anne (40), an accomplished runner, crossed the finish line 15 minutes earlier. "I was hoping for a time of four hours and 30 minutes."

Speaking two days after the event, a tired, sore and proud Steve said it felt "class to cross the finish line in near perfect conditions" even though it was a "real push" to get past the onslaught of ostriches and camels and even a Mr Potato Head.

His wife started running 10 years ago and in the last four years, Steve has been hot on his wife's hasty heels, participating in half marathons and even a half Ironman. What makes it even more impressive is that Steve has a foot injury from playing football. "I was told I wouldn't be able to play any more because of the trauma caused to my foot where bone had started to grow. But I was sore whether I rested it or not so it was a case of damned if you do, damned if you don't." He decided against a procedure which would entail getting screws in his foot and "just carried on".

While Anne qualified for the marathon, Steve's name got pulled out of the ballot. At the start, he wasn't sure he could take on the monumental challenge and only began fundraising in March. "To be honest I was just glad to get to the start line." He's already more than doubled his target raising close to £800.

Steve trained for the big event by run-



Steve Moore (left and above)

A race for LIFE

ning three times a week and swimming twice and kept his mind occupied on the big day by listening to everything from Chemical Brothers to Katy Perry.

'Big thing'

Hannah's mum Sasha is delighted at the "big thing" that Steve did for her amazing little daughter. "We really appreciate what



Siblings Ryan, Zoe and Hannah

he has done so a big thank you from us."

Sasha, a teacher, is also a tireless campaigner for Fanconi Anaemia and believes that a cure for Fanconi will lead to cures for many cancers.

There are 13 genes responsible for Fanconi Anaemia and one of genes is called FancD. Sasha believes that if this cancer can be cracked it will crack others as FancD is the same gene as the breast cancer susceptibility gene BRCA2. "A cure for Fanconi's will lead to cures for many cancers, I believe it is the missing link in cancer research."

"A better understanding of FA and cancer causing genes is in everyone's interests and that's why charities such as Fanconi Hope are so important as they fund research and collaborate with their USA counterparts Fanconi Anaemia Research Fund, to research better treatments."

She explains: "With Fanconi Anaemia, every cell is predisposed to being cancerous as the chromosomes are susceptible to breakage which cause cells to mutate."

Hannah was born on May 6, 2006, and was just three weeks old when Sasha and husband Mark received the devastating diagnosis. The shell-shocked couple were told she would most likely reach her seventh birthday, but thankfully, that milestone has long passed.

A breakthrough came when the devoted parents brought Hannah to Paris to see a doctor who specialised in the disorder. She had carried out the first cord blood transplant on a Fanconi patient and was convinced the same could be done for Hannah. The couple were elated and the following year, they conceived a healthy baby boy called Ryan. Unfortunately, his bone marrow didn't match Hannah's so the couple researched a type of IVF treatment which would involve the embryos being tested for genetic disorders before being implanted into the womb. "It's basically IVF with the extra stage of screening," explains Sasha.



Clockwise from top: Hannah in hospital; Hannah, Ryan and Zoe play in the forest; Steve and wife Anne after the race; Hannah at the Ulster Museum and the cord blood

Zoe's gift

In January 2010, Sasha and Mark travelled to Nottingham to start the cycle. Zoe, was born on November 15, 2010 and her blood was a match for Hannah, who incidentally came up with the name for her baby 'blood sister'. It turns out that it was beautifully appropriate as Zoe means 'life'.

Fanconi Anaemia, though not a well-known disorder, features on soap opera Emmerdale. Debbie Dingle's daughter Sarah suffers from the condition and Debbie's controversial plight to conceive another child to provide genetic material for Sarah has been portrayed. Charley Webb, who plays Debbie, has said: "It's all about individual choice. Personally, I wouldn't care what it took. I would do absolutely everything and anything to save my child." A similar storyline was portrayed in 2009 movie, My Sister's Keeper, where a child was conceived to be a 'saviour sibling' for an already existing child suffering from a form of leukemia.

Sasha is acutely aware that there are ethical issues around a so-called 'saviour sibling'. However, she says firmly: "I don't have any issues.

"The placenta and cord blood are usually incinerated and it is so useful because it does not contain any viruses which is good for stem cells. It should be saved."

"For me, it's about having a healthy family. Zoe was a much-wanted third child and the fact she could help her big sister too is wonderful."

Zoe's cord blood was syringed up into packs, frozen and then defrosted and infused into Hannah during a long, painful and risky procedure in 2012. Her immune system had to be shut down and she was in a lot of pain. It took up to three weeks for Hannah's new blood to settle into her body.

Since the cord blood transplant, Hannah's haematology problems are all but residual, but because the youngster is susceptible to cancer, she is regularly screened for things like mouth lesions.

Fearless Hannah

Despite her traumatic start in life, Hannah, who attends Meadowbridge Primary in Lisburn, is a ray of light. Sasha says: "She is wonderful, happy and makes friends easily. She is giggly, kind, strong in herself and works hard at school."

Just then, Hannah bounds into the room, Sasha smiles and says: "She's also a little rascal, and mischievous.

"She is so fearless and throws herself into things. She is also in Belvoir Players, does Irish dancing, judo (which made me so nervous) and cookery."

Hannah is very vocal about her illness and chats with her brother about how the many treatments she endures make her feel. Because of her medication, she has suffered hallucinations and she has frightening nightmares about spiders. "Hannah has a very good memory and can remember everything in sequence and how she felt."

One of the saddest things Sasha can remember her daughter saying is: "Mummy, what's the end of my numbers going to be? Will I be 16?" Sasha realised she was talking about the age she is going to die. "She is so sensitive. She has ideas, values and knows what she wants to be."

Sasha acknowledges that each decade brings advances in medical research so there is no reason not to be positive. "Everything is in Hannah's favour, the indicators are good."

Hannah can have surgery for her hands so she can have opposing grip but her mum is leaving the decision up to her. "She initially thought 'no' but it is her decision. She needs to be in the right place in her mind."

Sasha is at pains to mention Hannah's amazing classroom assistant, Mrs Colville who is helping Hannah become an independent young lady.

"Hannah has an amazing can do attitude, is confident and much less hesitant than her siblings."

Hannah encapsulates the independent, adventurous spirit of her favourite Disney character Belle and like Belle's loyal friends, her family will never, ever lose hope.

You can donate cord blood at the Royal, the Mater and via the NI Blood Transfusion Service - it is like a normal blood donation.

■ To make a donation to Steve, visit

justgiving.com

■ To make a donation to Fanconi Hope, visit

www.fanconihope.org

For more information, visit: www.nibts.org