



Danielle with Zahra

How and why was the ZB Foundation formed?

Born on October 8 2011, Zahra Beau Naqvi was a beautifully peaceful baby girl. However, she carried a disease from birth that would prove to be fatal. Zahra was from one of the poorest regions of Northern Pakistan and her birth mother, under pressure from her conservative family, was forced to abandon her at birth. This baby was given another chance when my husband and I adopted her but sadly, Zahra's fairy tale was cut short as she was diagnosed with Glutaric Acidemia Type 2 – a metabolic disease that occurs in 1 in 250,000 babies – when she was just four months old. She lost her battle with the disease on February 18 2012. Zahra may have lived had doctors performed just one simple

'heel-prick' test known as 'New Born Screening', which may have detected the disease sooner. So my husband and I created the foundation in her memory to give other babies the chance Zahra never had herself.

What is the goal and mission of the foundation?

Based in Pakistan, the foundation's initial aim is to pioneer the use of New Born Screening, target the uncharted medical area of rare metabolic diseases, and over time, become a compelling soldier in the fight against infant deaths. Through collaborating with clinics and hospitals, plus a comprehensive network of labs and doctors, parents in Pakistan will finally have the opportunity to provide their babies with the screening test for free in the name of the ZB Foundation.

5 minutes with...

Danielle Wilson Naqvi

Caring, compassionate and determined to make a difference, this mother of three tells us about the ZB Foundation inspired by the tragic loss of her adopted daughter

How has the journey been so far?

Zahra is making this charity come to life. We have met so many amazing people who have the unique experience we need – we are lucky to have one of the pioneers of New Born Screenings in Europe on our advisory board, along with one of the only genetic specialists in Pakistan. My in-laws in Pakistan help to drive the charity, and without them we would be struggling to operate.

Has your family grown since the loss of Zahra?

Yes, we have been blessed with three children since Zahra passed away. Amara is our eldest and we have two 15-month-old twins, Rio and Sienna. Our house is like a playground every day, yet it's so much fun! I think we may have one more, but we'll have to wait and see...

To find out more about the ZB Foundation, visit www.thezbfoundation.com

