



A Mother's Love MAKING A DIFFERENCE

procedure in health care systems across the West that involves drawing blood through a simple heel prick, which would then be screened for up to 40 diseases. The 37-year-old had never heard of it. The doc, however, kept putting it off, till finally he said there didn't seem to be any need and it was too late anyway (since the test needed to be carried out within 72 hours of the child's birth).

Zahra seemed fine for the first two months. After that, Danielle says, she started to "really foam" at the mouth. "My top would be soaking wet whenever I carried her. She'd be very lethargic, throwing up all the time... But she never cried. She was an angel child... always very peaceful..."

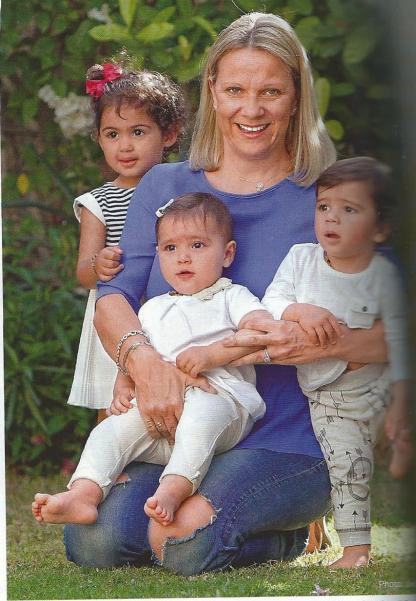
After more than three months, when Zahra didn't seem to be gaining much strength, the doctor suggested a thicker formula. Little did Danielle know that her baby was silently battling Glutaric Acidemia Type 2 – a metabolic disorder affecting 1 in 250,000 babies that prevents the body from breaking down proteins or fat for energy. She gave Zahra the formula and woke up the next morning to find her blue in the cot.

Rushed between three hospitals, the doctors worked their best for 16 days — before Zahra passed away at four months of age on February 18, 2012. "I was so angry, so heartbroken..." Danielle recounts, choking up. "I couldn't believe I'd waited so long for my baby, only for her to die in such a horrific way. I couldn't understand why, when there were a million babies abandoned each year in India and Pakistan alone, the one child we got to love died."

The tragedy eventually led to the creation of The ZB Foundation, which aims to pioneer the use of the newborn screening test in Pakistan (currently not done anywhere in the country) — by providing it free of cost for every child. And they are moving rapidly towards their goal.

In the last year, the foundation has teamed up with global health solutions provider PerkinElmer (who are offering the pioneering charity a manual machine that tests for eight diseases, till they raise the \$600,000 needed for the main diagnostic machine), top paediatricians who are on board with the cause and a lab chain that will do the tests themselves. In fact, the ZB Foundation is hoping to carry out the first newborn screening tests in Pakistan latest by April.

"Our biggest challenge right now is to educate the doctors," explains Danielle. Last month, the foundation was setting up on the morning of a conference in Peshawar, Pakistan (Zahra's birthplace) to raise awareness for the cause, when two obstetricians walked in. They were losing babies constantly,



DOTING MUM: Danielle with her children — Amara Beau (far left) and twins Ric and Sienna — at their Dubai home



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they despaired, succumbing to diseases they had no handle over — and they were desperate for an answer. "That's when we realised how much difference we could make. Even if all we do is give those doctors a system by which to detect disorders early and provide treatment options, imagine the number of babies we may save."

The Naqvis now have three children: Amara Beau, who they had the chance to adopt a month after the tragedy, and biological twins Rio and Sienna – but Zahra's legacy stays strong. "Take time to heal but take comfort in the fact that you were picked," Danielle says, to anyone dealing with similar circumstances. "You need to do something positive with the loss. It breaks my heart everyday but I believe Zahra came to us for a reason: to set up this charity and save lives. Doing this charity makes me feel so close to her — my baby who came from my heart, not my tummy, as I always say." W

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CHAMPION-ING CHILD RIGHTS

The ZB Foundation aims to target the uncharted medical area of rare metabolic diseases, especially in Northern Pakistan. For more info, visit www.thezb foundation.com

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In a horrific twist of medical negligence, a Dubai-based couple lose their baby girl — but grief gives way to a pioneering charity in Pakistan that is working to ensure no other parent has to go through what they did ever again

BY KAREN ANN MONSY

ritish expat Danielle Wilson Naqvi and her husband Akber always knew they wanted to adopt. In October 2011, a year after they'd started the process to do so from Pakistan, they got the call they'd been aching so long for: a baby girl had just been abandoned; would they like to see her? "We jumped on the first plane out and my heart melted as I held my daughter for the very first time," says the Dubai resident.

The couple stayed in Pakistan for two weeks to complete the paperwork and, overnight, little Zahra Beau – with her "dark hair and porcelain skin" - became their world. "I never let her go," Danielle recalls. The couple brought her back to Dubai and the new mum went "straight from the airport" to a paediatrician who'd been recommended to them, so she could "give her the best start in life".

Danielle distinctly remembers the doc asking if Zahra had had a neonatal heel prick test - a mandatory newborn screening