



Danielle and her husband Akber Naqvi with their children Amara and twins xxxxxxxx

## A SIMPLE TEST TO SAVE LIVES

*GC meets the inspirational mother behind the ZB Foundation, a charity which aims to provide essential newborn screening to babies in Pakistan's poorest regions.*

BY NATASHA TOURISH

**T**he subject of immunization conjures up mixed emotions in most new parents as they weigh the benefits versus side effects to their child's health. However, when it comes to preventative screening, parents take it for granted that their babies will be tested at birth, often without them even known, unless an illness is detected.

That peace of mind isn't a luxury that new parents in Pakistan are afforded. Pakistan is one of only a handful of countries in the world that doesn't carry

out standard preventive screening tests on newborn babies, and as a result hundreds of babies die before their first birthday.

When British businesswomen Danielle Wilson Naqvi and her Pakistani husband Akber Naqvi got married, they promised on the day of their wedding to adopt a baby girl from Pakistan, regardless of whether or not they could have their own biological children. In Pakistan, there are over a million baby girls abandoned every year, as girls in poor families are often seen as a burden on the family finances.

"This is why we choose a baby girl, we didn't want to deny at least one girl a chance at love and life," explained Wilson Naqvi.

However they never thought there would be a limit on their time with their adopted daughter Zahra Beau. But just months after they brought her home to Dubai from Pakistan, she passed away at hospital in Dubai.

Zahra was suffering from Glutaric Acidemia Type 2, a metabolic disorder that affects just one in 250,000 babies.

Had she been screened at birth with a simple heel prick test, it would have shown an abnormality, which would have warranted more tests and subsequent life saving treatment.

The PR executive who is now mother to a second adopted baby girl from Pakistan and has recently given birth to twins, set up the ZB Foundation in their daughter Zahra's memory, with the aim to save many more girls like her in Northern Pakistan. While newborn screening using a heel prick test and a device called an MS machine is a routine part of infant care in the first world, in Zahra Beau birthplace of Pakistan, this type of testing is not available. The ZB Foundation hopes to raise funds to run such a facility in Northern Pakistan with the ultimate goal of rolling out this vital newborn care in every hospital throughout the rest of the country.

### A Simple Procedure to Save Lives

The heel prick tests use a new technology known as 'tandem mass spectrometry' to identify more than 30 disorders in newborn babies. Serious illnesses that the tests pick up include: cystic fibrosis, the inherited disease that affects internal organs, particularly the lungs and digestive system; congenital hypothyroidism, a rare disease that can impair both physical and brain development, but is treatable if caught early; sickle cell disease, an inherited blood disease that needs treatment from the outset to prevent serious illness; and phenylketonuria, another rare condition that can cause mental disabilities, but is treatable if diagnosed.

While the heel prick can cause some minor discomfort to the baby, it doesn't require the more extensive blood sampling of earlier tests. And, most importantly, screening using an MS machine is fast, accurate and comparatively cheap.

The British entrepreneur and mum intends to purchase these potentially life saving machines from a company in Finland with help from donor



A simple heel prick test at birth could have saved Zahra's life.



Baby Zahra Beau.

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contributions.

"Contribution doesn't have to be monetary," she explains. "We also need people with connections in Pakistan who could, for example, help with the transportation of the equipment from the ports to the hospitals."

"Once we have this machinery, we need only a small room in a hospital to carry out this simple test. We will provide the training for the doctors and nurses," says Wilson Naqvi.

The ZB Foundation is also in the early stages of discussions with Imran Khan's Shaikat Khanum Memorial Trust- the biggest cancer hospital in Pakistan, and owner of a new hospital in the northern region of Pakistan. Wilson Naqvi would like to join forces to raise awareness among doctors about the importance of

carrying out this heel prick test and to raise enough funding to provide other hospitals and clinics in rural areas with the equipment.

"When I travelled to Pakistan to meet my second baby girl, Amara, I did the test myself and sent the results to Saudi Arabia to be analyzed," says Wilson Naqvi. Knowing this is something very few parents in Pakistan would have the means or knowledge to do, she hopes the ZB Foundation's work will mean parents can take their newborns home armed with lifesaving knowledge and peace of mind.

*For more information, visit [www.thezbfoundation.com](http://www.thezbfoundation.com)*