

Heart stopping: A mother's desperate battle to save her daughter's life

When Annabel Kelly, one of twins, was born in New York, she had a very serious heart defect. Her mother, Anita O'Donnell, tells Joy Orpen about the desperate battles that ensued to save this precious little girl's life

Published 18/01/2016 | 02:30



2 Mum Anita

with her two-year-old twins Annabel and Abbigael. Photo: Dave Conachy

Anita O'Donnell and her partner, Mark Kelly, have literally been to hell and back. For 18 months, they lived on an emotional precipice, day in, day out, not knowing if their little girl would live or die. They witnessed her distress, her pain, her valiant struggles, and they felt powerless to help her. Today, they are totally motivated by that terrible time, to raise funds for research, so other children will be spared that pain and anguish.

Anita grew up in a charming old farmhouse in the Ballyhoura Mountains in Co Limerick. She graduated from the University of Limerick in 2000. She then spent two years in hedge-fund administration in Dublin, before going to Bermuda to work in finance. "That's where I first met Mark," she volunteers. "He's from outside Galway. We got together in 2005."

Soon after, the couple moved to New York and became part of that band of ambitious, hard-working young executives populating the world of high finance. Nonetheless, they were delighted when Anita became pregnant in 2013. During her first scan, twins were detected. At the next scan, concerns were raised that one of the twins was smaller than the other. Shortly after, Mark and Anita learned that the smaller baby was suffering from intrauterine growth restriction (IUGR). This occurs when the foetus is not getting enough oxygen and nutrients from the placenta.

The baby was also diagnosed with tricuspid atresia, which is a life-threatening congenital heart condition, where the tricuspid valve between the right atrium and the right ventricle does not develop properly. Anita says one particularly blunt doctor told her that, given the baby's severe problems, they had "choices".

Anita volunteers that although she is pro-choice, she definitely did not want a termination. The doctor then pointed out that the possibility existed that the baby would simply "self reduce".

Anita took this to mean the baby would wither and die. "I threw up when I heard that," she says, "and I couldn't go back to the office that day." By now she was terribly frightened, but she says Mark was unbelievably caring and supportive. She also got comfort from a sympathetic paediatric cardiologist, who assured them the prognosis for the smaller baby was good, in spite of the problems.

Not long after, Anita and Mark moved close to New York Presbyterian Hospital because of its excellent reputation for treating babies with cardiac conditions. When the smaller baby stopped growing at 34 weeks, both infants were then delivered by Caesarean section on December 11, 2013.

Abbigael (Abbie) weighed a respectable 4lbs 7oz, while her little sister Annabel (Annie) weighed only 2lbs 7oz, with the additional disadvantage of having a "massive" heart condition.

Just eight days later, Abbie was already home, while Annie's battles were just beginning. At six weeks, she had her first open-heart surgery, when a band was put on her pulmonary artery to slow blood flow. It went well. But soon after, Annie started to deteriorate.

"She was turning blue, and she was inconsolable," says Anita. "So when she was about 10 weeks, they operated again. This time they put in a shunt, to increase blood flow."

Annie was in theatre for several hours, and was on a ventilator for five days. Yet again, she failed to rally. "Her heart rate and oxygen levels were going down, but they didn't know why," says Anita. "Eventually they discovered she was in withdrawal from her medication, so they had to wean her off more gradually."

The goal then for the medical team was to increase Annie's weight to a point where it was safe to perform a Glenn shunt, to override the undeveloped section of the heart. However, she wouldn't take a bottle, so a tube was inserted for feeding purposes, with limited success.

Then, one Sunday morning, when she was almost five months old, a near-catastrophe occurred when the original shunt failed, causing a clot, which prevented blood getting to Annie's lungs and oxygen to her body. She almost died. Anita and Mark dashed to the hospital. "They were trying desperately to resuscitate her, but nothing was working," she recalls. "They needed to stabilise her urgently for surgery. They let us see Annie before she went into theatre. There were probably 40 medical people in the room; many of them crying. I was pleading 'fix her'."

Miraculously, Annie survived having another, bigger shunt inserted. In the meantime, her parents were warned that she was likely to have suffered irreparable brain and multiple organ damage due to oxygen deprivation. They just didn't know what to expect. But test after test showed no significant long-term damage from the episode.

Anita believes it was prayer that saved this very special little girl. "So many, many people in Ireland and the US lit candles and prayed for Annie," she says. "I honestly believe she is with us thanks to the power of prayer. I believe she pleaded with God when the doctors were trying to revive her, and said she had a lot more to do on this Earth, and that he should let her come back. And he did. There wasn't any doctor that thought she could survive and be normal."

However, Annie was still extremely sick, and in need of further heart surgery. When she was nine months old, she finally had her Glenn shunt operation. This major reconstruction helps compensate for the faulty valve. The doctors anticipated Annie would require months of in-patient rehabilitation after the Glenn, but to everyone's surprise, just two weeks later, she went home. She will require further surgery in the future, but for now, she is doing exceptionally well. An old photo of Annie post-surgery, shows her lying buried beneath a maze of wires (inset, above left). However, recent videos reveal a gorgeous little girl, running around like any other two-year-old.

"Cognitively, Annie is doing fantastic. However, she is still a little weak physically, so she has regular occupational, speech and physical therapy, which has made a huge difference," Anita says.

There is no doubt Annie owes her life to her nurses and doctors, and to the devotion of her parents and supportive extended families who fought for this brave poppet.

Anita and Mark are establishing the Annabel Rose Kelly Foundation to raise funds for research into congenital heart disease. All proceeds will be donated to the Children's Heart Foundation.

For more information, see facebook.com/annabelrose.kelly, or see childrensheartfoundation.org. To make a donation, see weblink.donorperfect.com/NewYorkAnnabel

Sunday Indo Life Magazine