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Local News



A mother's brave memoir of her son's brief life

'Waiting for Gabriel' inspires faith in the healing power of love

By John Rosengren

"Waiting With Gabriel" opens when the author and her husband learn five months into their pregnancy that the baby she's carrying has a congenital heart defect. One that will let their baby live perhaps a week — at the longest. You won't read this book without crying. But you will be glad you did. Amy Kuebelbeck's brave memoir will change you.

This first book from the award-winning Associated Press reporter and editor deftly avoids the easy traps of maudlin sentimentality or self indulgence. Kuebelbeck lets the poignancy inherent to the situation drive the narrative, engendering compassion and understanding. In the end, the reader emerges with the author to cherish life itself more deeply.

An ultrasound reveals that Gabriel has hypoplastic left heart syndrome (HLHS), meaning the left side of his heart hasn't developed properly.

Kuebelbeck reports that congenital heart defects are the leading cause of infant death. HLHS occurs in one of about every 5,000 births and affects approximately 1,000 babies — and their families — in the United States every year. Gabriel's story puts those statistics in the context of a family.

Kuebelbeck and her husband, Mark Neuzil, a college journalism instructor, face an awful decision. They can opt for a traumatic series of corrective surgeries, gamble on the remote chance of an available heart for transplant, or let their son die naturally. They do not know how long the surgeries or transplant might prolong their son's life; the only guarantee those procedures carry is pain and suffering. "It seemed to us that the Solomonic choice we were being asked to make on behalf of our son was not between life and death but between a painful death and a peaceful one," she writes.

Medicine cannot save their son. "Our culture clings to a number of comforting myths about modern medicine, including the ideas that technology can fix everything and that finding a cure is just a matter of hauling oneself to the right hospital," Kuebelbeck writes. But, she learns, sometimes it just comes down to you and life. And death.

God cannot spare their grief. Roman Catholic by birth, and "spiritually intrigued and institutionally skeptical" by her own description, Kuebelbeck and Neuzil are comforted to meet a sympathetic priest remarkably knowledgeable about HLHS in Father Bill Baer. He waits patiently with them, ministering to them with his presence.

"Fortunately, we had already stumbled across the idea that God was grieving with us. . . . As the waves of grief tossed us end over end, slamming our faces into the sand, we clung to the belief that God was not abandoning Gabriel or us."

This belief sees the couple through excruciating moments such as a shower for the healthy baby Kuebelbeck's sister carries, shopping for a miniature coffin and saying goodbye to Gabriel. Throughout, Kuebelbeck and Neuzil gracefully shoulder their grief.

Kuebelbeck concludes that perhaps Gabriel's legacy will be to pave the way for others' grief. Indeed, this memoir's honest and open narrative advances awareness of the pain experienced by families that lose babies — through miscarriage or otherwise. It validates their grief and affirms their healing. "Waiting with Gabriel" is an important contribution to a subject area long dominated by the hopelessly sentimental novel "The Christmas Box."

Beyond that, Kuebelbeck's tender voice and graceful story inspire hope for anyone beset by pain and suffering.

Medicine may not be able to prevent it. God may not spare it. But love sees them through it.