

## Remembering Haley December 2005



It seemed like a normal pregnancy. Ann Jerome and her husband, Brad, already had one child, Griffin, and were anxiously anticipating the arrival of a second.

Three weeks before the due date, though, things changed. A prenatal test showed something was very wrong. Ann and Brad soon became acquainted with the condition known as trisomy 18 – and the difficult choices that came with that diagnosis.

Trisomy 18 is a chromosomal abnormality where there is an extra chromosome present in every cell of the body. Studies show one in 1,500 children are diagnosed prenatally with the condition; only half that number are born alive at full term. Of those who survive to birth, only half make it to two months of age, and only 10% survive to their first birthday.

“We were given three choices,” Ann says, “and none of them were good.” They could allow the child to die before birth; give birth and keep the child alive artificially for six to 12 months at most; or give birth and sign off on any life supporting measures.

“We chose the third option because it gave us more control,” Ann says.

That still didn’t make things easy. Griffin was ready to sign up for kindergarten, and it was difficult to be around well meaning and well-wishing family and friends.

“Fortunately, our doctor understood our predicament,” Ann says, “and knew of someone who could help us through this situation.”

Ann gave birth to Haley Jerome on August 13, 1992. Within hours, Haley died. Ever since then, Ann has wondered what Haley would have been like as a six year old, as a teenager ...

What she does know, though, is that she and her husband were lucky. And that’s why Ann is so committed to the Kansas City Partnership for Pediatric Palliative Care, a program of the Center for Practical Bioethics. Ann is a member of the initiative’s advisory council.

“We were lucky our doctor did more than give us choices,” Ann says. “He had real empathy for our situation.” Ann also says a situation like that either pulls a family apart or seals the deal. “We stayed together and now have a healthy 5 year old boy, Brandon.”

Ann says there are so many more resources now. “We needed someone then,” she says. “We needed to know we were not alone.” Ann says the Center’s program will be especially helpful to families facing similar situations. Program goals include enhancing professional competencies and establishing viable family resources, both of which would have been particularly helpful to the Jerome’s 13 years ago.

Today, Ann Jerome is the executive director of the Ronald McDonald House in Kansas City. It’s her job to help families with babies on life support. And every August 13, Ann and Brad deliver meals to the families at Ronald McDonald House.

It’s their way of remembering Haley.

For more information on the Kansas City Partnership for Pediatric Palliative Care, click [here](#).