

Happy Birthday, Baby Doe

By Mark W. Leach
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Twenty-eight years ago today, in Bloomington, Ind., a baby boy was born. Though his parents may have given him a name, that child became known as "Baby Doe." Why "Baby Doe"? Because that is how the lawsuit filed after his birth referred to him.

What did Baby Doe do to start a court fight? Nothing, exactly. He entered the world without his esophagus connected to his stomach — a condition that can be repaired, and with a 90 percent success rate. The lawsuit started because of the reason his condition was not treated.

In addition to having a repairable condition, Baby Doe was born — conceived, in fact — with Down syndrome. The parents' physician, Dr. Walter Owens, advised that they could choose to do nothing about treating their child's esophagus. Although this would result in Baby Doe's death, Owens relayed how some children with Down syndrome were "mere blobs." Based on their doctor's advice, the parents chose to withhold care.

Attorneys for the hospital and for families wanting to adopt Baby Doe sued for court-ordered medical treatment. Owens testified, as did another doctor, who directly contradicted Owens, saying that care should be provided to this living human being who had a non-terminal condition.

Meanwhile, Baby Doe was sent off to a corner in the hospital's nursery. His lips cracked from dehydration. Doctors tried to intervene, but Owens blocked them — even physically — from rendering care to Baby Doe.

The judge ultimately ruled that because there was a difference in medical opinion, the parents were within their rights to choose to withhold care.

The disconnected esophagus caused Baby Doe's stomach acid to bleed into his lungs. He spat up blood. Six days after being born, Baby Doe died.

I heard this story four years ago while on a shuttle to Kansas City's airport. I had just attended the first Down Syndrome Affiliates in Action (DSAIA) conference. Being a lawyer, I was ashamed at the idiocy of that judge — under his ruling, if doctors did not agree, that constituted a difference in medical opinion, regardless of how unreasonable Owens' medical opinion was. Being a father to a daughter with Down syndrome, I was enraged.

But I thought — or hoped — that such abuse could not persist today. Not in this age of acceptance of diversity, respect for human rights, and political promises that health care is a right.

Then I read about the Groningen Protocol. In 2005, physicians in the Netherlands formalized a practice for not just withholding care but actively causing the death of infants born with disabilities. Some of its first victims were babies born with Down syndrome.

And 2009 closed with the publication of a Russian article entitled "Finish them off, so they don't suffer." The author argued that parents should have the right to "post-birth abortions" for those children they do not want because of the child's disabilities. In an interview, he stated, "I don't want a baby with Down syndrome," and that he should not be stopped from avoiding having one, even if that child was breathing in the next room in a nursery.

The Russian columnist is not alone in his views. Here in the United States, Princeton University bestowed its first professorship of bioethics upon Peter Singer, a man who has espoused similar, if more nuanced, views about the right to postnatal killings in the case of disabilities.

Of course, the Russian column and Singer's views are just that: opinions. Owens and the Groningen Protocol actually act upon the view that certain lives are not worth living.

While we would like to think that Owens is from a distant, ignorant past; that

the Russian columnist is a crackpot half a world away; and that Singer is just a voice from the Ivory Tower, here is a very real story that happened, and continues to happen, in this world today.

In March 2010, DSAIA returned to Kansas City. This year, international attendees included Bala Mohammed, the leader of a local group in Nigeria. His tale makes Baby Doe's treatment look humane.

Bala has a niece with Down syndrome. He told of how, culturally, his niece was considered a curse, but his sister refused to accept such a notion. Instead, she chose to keep her baby, and now her daughter is flourishing. However, Bala shared the fate his niece easily could have faced.

A local sanitation worker showed up to work one day to burn a garbage heap. The worker approached the trash pile and was about to light it ablaze, but he stopped. He stopped because he thought he heard a moan. He saw a burlap bag resting on top of the trash pile and, when he opened it, he found inside a toddler — a little girl with Down syndrome.

Twenty-eight years after Baby Doe was born and Owens advised his parents to let him die from neglect, a child was put in a sack and left on a trash heap to be burned to death. What's more, physicians in the Netherlands, a columnist in Russia and an Ivy League professor would say that the little girl's parents were within their rights.

On this anniversary, we would like to think that the world and people's understanding of Down syndrome has changed, but clearly, that isn't always the case. So we are left to wonder, what can we do to ensure that the next Baby Doe born will have the chance to live and see his or her birthday?

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FORUM

"Government needs to have both shepherds and butchers."

VOLTAIRE (1694-1778), French historian and dramatist

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