

# Parents vs. doc

In the treatment of children with severe genetic disabilities, the interests and opinions of parents and doctors aren't always the same—and hospital futility policies may become the flash point of the fight

by COURTNEY CRANDELL

**W**hen doctors diagnosed Abigail Allison with Wolf-Hirschhorn syndrome in 2004, they said she wouldn't live beyond two years. They told parents Rex and Dawn to take Abigail home with hospice care. Wolf-

Hirschhorn syndrome, caused by deleted genetic material associated with the fourth chromosome, affects 1 in 50,000 infants and causes delayed growth and intellectual development as well as seizures. About one-third of those who have it die within two years after birth, depending on the severity of the disorder.

But Rex, a school psychologist, and Dawn, a physician, wanted to do more than hospice care for their daughter. The trouble was, they had a hard time finding doctors who agreed. They often had to fight against the medical community to get the care they thought their daughter deserved.

When Abigail suffered a seizure at 11 months old, the emergency room doctor delayed treating her, eventually informing her father he wasn't obligated to provide medical care. Another doctor

told the Allisons he wouldn't spend healthcare dollars on Abigail for a blood test.

When the Allisons took Abigail to the hospital again for a virus three years later, the doctor treating her said he wouldn't resuscitate her if she stopped breathing. Doctors placed a "do not resuscitate" (DNR) order on Abigail's chart without her parents' knowledge.

"It was my understanding that you had to have written consent if you're going to put a DNR on their chart," Dawn Allison said. "I never imagined this would happen in the United States." The doctor removed the DNR from Abigail's chart at her father's request. But Rex Allison believes the doctor



COURTESY OF THE ALLISON FAMILY

# Doctors

agreed only because of the couple's medical knowledge and understanding of Abigail's disability.

For years, the Allisons and other parents of children born with severe disabilities have battled fertility policies common at many hospitals across the United States. If doctors consider a treatment "futile," according to a hospital's policy, they are not obligated to provide it. That can leave parents feeling as if they have no control over what happens to their children. But doctors also face a dilemma when treating incurable and fatal genetic disorders: How do they balance the parents' wishes with what's in the child's best interest?

**A**t least two state legislators believe hospitals should be more clear with parents about their fertility policies and obtain parental consent before issuing DNRs or withholding treatment.

Oregon state Sen. Tim Knopp has introduced a bill that requires hospitals to inform

*The Allison family (left); Abigail Allison (right)*



parents of their futility policies. The bill, which is awaiting a committee hearing, also mandates parental consent for withholding treatment and food from minor patients and for issuing DNRs. He crafted his bill after the Allisons brought the issue to his attention.

Dawn Allison had discovered how difficult finding a hospital's futility policy can be when she attempted to determine whether her local hospital, where she has courtesy staff privileges, had one. It does, but she could only confirm it after several days of phone calls. She eventually had to contact a palliative care physician to get an answer.

"If it is this difficult for a physician affiliated with a hospital to find its futility policies, I would suspect it would be more difficult for someone else to get this information," she said.

In Missouri, state Rep. Bill Kidd filed a similar bill, known as "Simon's Law," at the end of last year. It's named for Simon Crosier, who died three months after being born with Trisomy 18 in 2010.

Doctors suspected Simon had the genetic disorder before he was born, but his parents



Knopp

## From passive to active euthanasia

Doctors who provide inadequate care for babies with genetic disabilities are participating in "passive euthanasia," Dawn Allison told me. But in the Netherlands, doctors' approach to disabled infants has surpassed passivity to become active euthanasia.

In a position paper recently released by the Royal Dutch Medical Association (RDMA), the organization announced doctors may stop administering nutrition and fluids artificially if they determine treating a baby is medically futile. According to RDMA, treatment is futile if it doesn't extend a short life expectancy, if the prognosis and quality of life are poor, or if the baby faces a life of unmitigated suffering.

Under "good palliative care," RDMA also outlines three cases when euthanasia by administering muscle relaxants is justifiable for these infants: If the baby is visibly suffering, if a prolonged dying process is distressing the parents, and if the baby is already receiving muscle relaxants for his or her treatment.

The new directive will affect about 650 of the 175,000 babies born in the Netherlands annually. —C.C.

refused conclusive testing due to the miscarriage risk. After he was born, Simon was labeled "incompatible with life," his mom Sheryl Crosier told LifeSiteNews.

Doctors changed his treatment options, abandoning most aggressive measures. They fed him sugar water instead of the breast milk Crosier pumped for him. And they placed a DNR on Simon's records without the Crosiers' knowledge.



Simon Crosier with mother Sheryl and father Scott

The doctors also stopped giving Simon medication to help his heart, although he did undergo reparative heart surgery.

"We wanted the doctors to look at our precious son as if he didn't have that label," Crosier said of the "incompatible with life" designation. "We wanted them to treat Simon with their God-given talent and leave the rest in God's hand."

When a child is born with a genetic disorder, doctors often don't know the severity, said Robert Orr, a retired physician ethicist and Christian ethics consultant. Before determining treatment options, doctors wait for the condition to "declare itself." If parents want to support the child initially, doctors should oblige their decision, Orr said. If the child's life expectancy is short and parents simply want to cuddle their child, doctors should support that as well.

But if parents and doctors continue to disagree as time progresses, then begins the delicate task of balancing doctors' knowledge, the parents' wishes and grief, and the best interests of the child. "Often times, it's a major conflict," Orr said.

When conducting an ethics consultation, Orr discusses the situation with all the parties involved and examines relevant literature. Then he evaluates the best interest of the child: Is the child in pain? Will the treatment alleviate pain? Will the treatment heal?

Sometimes Orr's consultations involve difficult choices when babies are dying, parents insist on treatment, and nurses are crying at the infant's bedside because that treatment causes more pain. "We must respect the right to life, but we also have a duty to alleviate suffering," Orr said.



Although Simon Crosier and Abigail Allison both had doctors place DNR orders on their charts without their parents' consent, such drastic measures aren't common. But they do happen, even over family objections in limited circumstances, Orr said.

In Orr's experience, doctors issue such orders when the patient suffers without relief and is unlikely to survive, but the family insists on treatment. Many of those policies require approval from a second physician and familial notification.

"From an ethics perspective, I believe such an order should not be written without notification of the family that it is being done and why," Orr said.

Over the past 20 years, the approach to medical treatment has changed, said David Levine, a Christian neonatologist and director of Newborn Services at Columbus Regional Health in Georgia. Before, parents usually were content to allow doctors to control their children's treatment. And medical professionals saw themselves as protecting the patients and parents from ugliness, particularly the suffering experienced by babies with genetic disorders.

But now, parents want more involvement in the decisions surrounding their child's medical care. Many think they can demand any desired treatment, but Orr said that is not the case in every situation.

Still, doctors need to carefully consider parents' wishes while guiding them toward decisions in the best interest of the child, Levine said. Doctors should seek to provide aid where they



can. They're also obligated "to make sure that when we're prolonging life, we're really prolonging life and not prolonging dying," Levine said.

No blanket criteria exist for making those decisions. Even in the midst of all the complexity and grief, Levine said, "we have to make decisions that help our patients—not just dispense with an ugly situation."

Levine's own approach to treating genetic disorders has grown with experience. As a young doctor, he helped a family whose child was born with a genetic disorder. He saw how Katie filled her family's life with love, despite her disorder. And though Katie died from complications several years later, caring for her "made such a difference," Levine said. "It changed my whole attitude."

Doctors' medical knowledge of genetic disorders also is changing. For example, Down syndrome, which affects the 21st chromosome, was grossly misunderstood for many years. In the early 1900s, doctors didn't expect persons with Down syndrome to live beyond 9 years. Now, most live to 55 years and older, thanks to improved care and better understanding of the disorder.

Doctors said Abigail Allison wouldn't live beyond two years, but she's now 11 years old.

She can walk on her own with assistance from a walker. And though she can't speak yet, she can communicate with her family.

Abigail impacts everyone around her, Rex Allison said.

"If we had listened to the information given when she was born," he said, "she wouldn't be here to do that." ☉

—Courtney Crandell is a writer in Virginia



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LEVINE: HANDOUT • ORR: HANDOUT

KNOPE: DON RYAN/AP • SIMON: COURTESY OF SHERYL CROSIER

## The fight for Baby K

Tension between parental wishes and medical authority is nothing new. In 1982, a Virginia mother made national headlines when she took her fight for her daughter's life to federal court.

Shortly after baby Stephanie Keene was born with anencephaly, her mother began a long battle with a Fairfax, Va., hospital for the care she wanted the child to receive. After months of disagreement, the case landed in court when Stephanie returned to the hospital for a tracheostomy to treat respiratory problems. The hospital sought a court order for an appointed guardian and palliative care.

The case eventually went to the 4th U.S. Circuit Court of Appeals. The hospital argued any life-sustaining treatment was futile. But a year and four months after Stephanie's birth, the appeals court ruled in the mother's favor. The hospital could not decline care for Stephanie's respiratory distress because hospitals provide care for other patients with terminal diagnoses, the court said.

Stephanie survived in a pediatric intensive care unit until about a year after the ruling, living to almost 2½ years old.

—G.C.