Children's Healthcare Is a Legal Duty, Inc.

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Equal rights for children under the law



Douglas Swan with son Matthew

Defeat in Iowa again

Two years of hard work by child advocates ended in defeat on February 21 when Representative Kraig Paulsen, R-Cedar Rapids, the chairman of the Iowa House Judiciary Committee, disclosed his intention to kill a bill repealing two of Iowa's religious exemptions from child healthcare laws.

In 2004 Representative Kevin McCarthy, D-Des Moines, agreed to sponsor a bill to repeal some of Iowa's religious exemptions. My husband and I, the founders of CHILD, decided to do everything within our resources to get the bill passed.

We asked for a bill that repealed three of Iowa's most unusual religious exemptions. We thought confining the bill to those would help legislators be more comfortable with it.

One was in a code chapter on how school systems handle handicapped children. It states in

part: "No provision of this chapter shall be construed to require or compel any person who is a member of a well-recognized church or religious denomination and whose religious convictions, in accordance with the tenets or principles of the person's church or religious denomination, are opposed to medical or surgical treatment for disease to take or follow a course of physical therapy, or submit to medical treatment. . . ." Iowa Code 256B.8, third unnumbered paragraph.

We felt this law prevented the state from requiring medical treatment or therapy for a handicapped child who belonged to a church with beliefs against medical care. Few states have religious exemptions directed toward handicapped children, and Iowa is the only one giving an exemption based on a handicapped child's church membership.

Many months later we learned that the education law might mean only that school personnel themselves cannot require medical treatment for children, but they should, under other chapters in the code, nevertheless report to the Iowa Department of Human Services (DHS) when they believe a child is being medically neglected.

A second religious exemption permitted courts not to order medical care for children whose parents were indigent and had religious beliefs against it.

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Iowa Code 255.10. No other state has a law like it. We privately called it Iowa's "stinginess law."

Iowa's religious defense to manslaughter

The third religious exemption repealed by the bill was a defense to felony child endangerment and manslaughter. It stated that parents cannot be charged with willfully depriving a child of health care when they withhold medical treatment from the child on religious grounds. Iowa Code 726.6 (1)D. Iowa is one of only three states with a religious defense to manslaughter.

Bipartisan sponsorship

McCarthy got Reps. Joe Hutter, R-Bettendorf; Jim Van Fossen, R-Davenport; and Dawn Pettengill, D-Mt. Auburn, to co-sponsor the bill.

The bill was assigned to the House Education Committee and then a subcommittee chaired by Rep. Rod Roberts, R-Carroll. Roberts decided to study it over the summer.

During 2005 the legislature reformed Medicaid laws. In the process they removed a code chapter that included 255.10 allowing courts to refuse to order medical care for a child when indigent parents raise religious objections. It seems that the Iowa legislature repealed a religious exemption without noticing what they were doing.

Through the summer and fall Doug and I traveled around the state meeting with members of the Education Committee in their home districts.

Proponent Testimony

In January Roberts held a hearing on the bill, House File 368. I testified in part as follows:

"We believe children should have the equal protection of the laws. The state has two mechanisms for protecting children: first, laws requiring parents to provide children with the necessities of life and second, laws allowing Child Protection Services to intervene and obtain these necessities for the child through court orders. We believe all children deserve the benefit of both.

"Iowa's felony exemption allows parents to "willfully' deprive a child of 'necessary health care" and thereby cause 'substantial harm' to the child if



CHILD Co-founder Rita Swan Credit for all House hearing photos: Michelle Leland

medical care conflicts with the practices of their 'recognized religious denomination.'

Feds forced states to enact religious exemptions

"It came into Iowa law in 1978 during a period in which the federal government coerced states to pass religious exemptions to child neglect in order to receive federal funding for child protection programs. Iowa enacted not only the required neglect exemption, but also an exemption to felonies.

All caregivers should provide medical care necessary to prevent substantial harm

"With repeal of the exemption, Iowa's endangerment law would be a very reasonable standard for all parents to meet. It requires only the medical care that is necessary to prevent substantial harm to the child. It does not require medical care for every scrape or sniffle. And willfulness is a pretty high standard for a prosecutor to prove. An Iowa Deputy Attorney General says that willfulness means that the parent has a conscious awareness that he or she is depriving the child of necessary health care and knows that it is not right. "Surely Iowa should require <u>all</u> caregivers to obtain medical care for a child when they <u>know</u> that they are depriving the child of health care that is necessary to prevent substantial harm and can afford to pay for medical care or obtain it from public services.

"This is an Iowa problem. A pediatrician and I reviewed 172 deaths of U.S. children in faith-healing sects in 34 states; two of the deaths were of Iowa babies. A Sioux City emergency room physician has a testimony in your packets about a case he saw last year.

"Iowa Department of Public Health (IDPH) data show that more than 2,000 Iowa children in K-12 schools had religious exemptions from immunizations in 2004-05—a 50% increase in just the last six years.

Vaccine-preventable disease outbreaks

"At one school in Jefferson County, Iowa, only 59% of the K-12 pupils were fully immunized in 2004.

"Two recent articles in the *Journal of the American Medical Association* indicate that students with personal belief exemptions increase risks to vaccinated children and are 22 to 35 times more likely to contract measles than their vaccinated peers. Daniel Salmon et al., *JAMA* July 7, 1999:47-53; and Daniel Feikin et al., *JAMA* Dec. 27, 2000:3145-50.

"Iowa has had several disease outbreaks related to religious exemptions from immunizations. One in 2004 cost the IDPH \$142,000 to manage.

"Last fall five cases of polio were found among unvaccinated Amish children in Minnesota. The IDPH has consequently made new efforts to increase vaccination rates among Iowa's Amish. The last U.S. cases of polio from the virus in its natural form were also among the Amish, including Iowa's Amish children, in 1979.

"With disease outbreaks increasing in Iowa (more than 1000 cases of pertussis last year, for example), it is important to have laws clearly requiring that parents get medical care for sick children regardless of their religious beliefs. HF368 does not repeal Iowa's religious exemption from immunizations, but does require all parents to get necessary health care for seriously ill children. "The law should extend its protections to all children. Laws depriving one group of children of protections afforded to others are, in our view, discriminatory and violate America's finest traditions.

"We believe our support for HF368 is in the best interest of parents as well as children. Many parents in faith-healing sects are very conflicted when their child is ill. What do you want the law to say to these parents? Please make your expectations clear to them.

Older than written law

"Children are dependent on parents to protect and provide for them. It is simply not right to allow parents to deprive a child of the vast resources of modern medicine.

"I will never forget the closing words of a prosecutor: 'The law that parents will do <u>everything</u> in their power to safeguard the life of a child is older than written law. It is the very basis of the social contract. It is a law of nature. It was the law when we were living in caves, and if it weren't the law, none of us would be here.'

"Please make this ancient and modern truth the law in Iowa."

Clear laws prevent deaths

Doug Swan spoke about the experience of Oregon and Colorado after they repealed religious exemption laws. Both states had many deaths of children in faith healing sects before repeal. Only one child's death due to religion-based medical neglect in those states has come to CHILD's attention since repeal.

South Dakota legislator lost child when she belonged to faith-healing sect

Five other proponents testified. Representative Joni Cutler, R-Sioux Falls, came from Pierre, South Dakota. She said that the courts have long ruled that a child's right to live takes precedence over a parent's right to practice religion when those are in conflict. Laws should require parents to get medical care for seriously ill children, regardless of their religious beliefs, she argued.



Cutler is an attorney, a professor, and chair of the South Dakota House Judiciary Committee. In the 1970s she and her first husband belonged to a Sioux Falls faithhealing sect called End Time Ministries. Their first baby died without medical care four days after a home birth.

In 1990 she lobbied against South Dakota's religious exemptions. A bill repealing five of

them was enacted. She told the Iowa legislators that no South Dakota children had died due to religious beliefs since 1990.



Peter Hetherington, a pediatrician at Blank Children's Hospital in Des Moines, testified in support of the bill. He pointed out that many doctors believe in the power of prayer and support families' reliance on it. He acknowledged that medical science cannot heal all conditions and that he's seen healings which medical science does not explain,

but nevertheless, parents need to bring seriously ill children to medical attention so they can be diagnosed and get medical treatment if it will prevent substantial harm.

Kathryn Skilton, a sophomore at Nashua-Plainfield High School and CHILD's policy intern, testified about the growing threat of infectious disease. She said those who refuse to seek medical treatment compromise the welfare of the whole community, not just themselves.

Skilton has done many projects related to religion-based medical neglect of children over the past four years. As a seventh grader, she wrote a paper on the issue for the National History Day competition. She won her division in Iowa and competed at nationals. In eighth grade she won first prize in Iowa's Write Women Back Into History contest with an essay about me. In ninth grade she submitted an essay in support of the religious exemption repeal bill to *The Des Moines Register* and was selected by the newspaper as one of its "young adult contributors."



Skilton addresses House subcommittee

In tenth grade she addressed the state Parent Teacher Association (PTA) convention in support of the repeal bill and undertook her most ambitious project: creating a DVD about the bill and sending copies of it to about 400 Iowa high school government classes. She conducted filmed interviews with Representative Kevin McCarthy, the Swans, and Iowa Secretary of State Chet Culver. Her webpage is at www.operationteenpower.org.

She repeatedly tried to get on-camera interviews with the Iowa Civil Liberties Union and Christian Science officials, the known opponents. She offered to submit questions in advance, emphasized that she wanted only a few minutes of their time, etc. After months of delay, the church officials finally said they would consider doing an interview only if they were given in advance videotapes of the entire interview with Rita and Doug Swan. Skilton refused.

Reverend Charles Curl, the pastor of the Norwalk United Methodist Church, testified as follows: "Children have the right to life and health just because they are alive. This right should not be seen as coming through anyone else, including their parents. The child has the right to good health himself or herself. The only choice that ever matters is the choice to preserve the life of these children through <u>all available means</u>, never by making a choice for only some available means.



"HF368 is about avoiding the either/or trap. Under Iowa law, no one should be allowed to choose to withhold usual medical interventions that can save the lives of our children who can die from easily treated maladies like pneumonia, bacteriological infections, obstructed bowels,

and diabetes, to name a few.

"HF368 acts to make both standard medical practice, along with other means, like prayers, the only good choice for the children of Iowa.

"I encourage the passage of HF368, as a clergyperson, as a former foster parent, and as an advocate for the lives of the children of Iowa."



Sherry Brown testified in support of the bill representing the Iowa Parent Teacher Association. She pointed out that the Iowa PTA first called for repeal of Iowa's religious exemptions from child health care laws in 1991.

Opponent Testimony

All opponent testimony was by Christian Scientists and Maharishis. Picking up on my reference to a law of nature, George Gregory, lobbyist and public relations manager for Iowa's Christian Science churches, agreed that it is natural for parents to protect their children. "We all love kids," he said. "But I turn first to God because God is omnipotent and God is love."

He told of a spiritual healing his family achieved for his 4-year-old daughter. She got blotches and breathed abnormally. They prayed for an hour and she got well.

"That's the kind of healing we find often," Gregory said. They've had many more spiritual healings and they know that Christian Science is the best health care for children, he said.

Gregory said that the Asser-Swan *Pediatrics* article reporting on 172 deaths of children after medical care was withheld on religious grounds had "been reviewed and found to be biased."

Iowa's child death review team has not seen a death related to religion since 2000, he said.

Do Iowa parents have a duty to provide lifesaving medical care?

Representative Kevin McCarthy, the bill's lead sponsor and also a deputy prosecutor "confirmed" that they can "still prosecute" under current law, Gregory claimed.

This statement about prosecution was highly misleading. McCarthy said what he actually told Gregory was that, while prosecutors can file childin-need-of-assistance petitions when the DHS knows of a child at risk of harm, HF368 is needed to make possible endangerment or manslaughter charges.

Principle more important than child's life

Eileen Dannemann, a practitioner of the Maharishis' transcendental meditation, attacked the alleged dangers of mercury in vaccines. She claimed vaccines had "wrecked" our school systems by creating "an epidemic" of attention deficit disorder, autism, and other neurological problems.

She claimed a U.S. Supreme Court ruling upholding the right of conscientious objectors to refuse military service indicated that parents had a constitutional right to withhold medical care from children on religious grounds. She quoted former state legislator William Witt as saying that it is better to let a child die of a vaccine-preventable disease than to violate a constitutional principle.

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Maharishi pediatrician testifies

Dr. David Sands represented himself at the hearing as a retired pediatrician. Only weeks later did CHILD learn that he was also a director of the Maharishi Enlightenment Center in Des Moines and, according to his web page, had "integrated Maharishi Ayur-Veda with his clinical practice" as a pediatrician.

Like Dannemann, he focused on the alleged harms done by vaccines although the bill did not change Iowa's religious exemption from immunizations.

Sands said the number of children affected by religious beliefs against medical care was so small that the legislature should focus on more "pressing problems" instead.

Children are lost under medical treatment

Lucille Gregory, wife of the Christian Science lobbyist, said that she lost a child under medical treatment before she converted to Christian Science. Therefore, medical science is not perfect and parents should be allowed to use other methods of healing instead. No doctor in Iowa can guarantee that he can save a child's life, she said.

HF368 privileges a business, and it is wrong to privilege one form of health care above others, she argued. "Christian Science is a legally recognized form of health care," she said.

She also told the legislators, "Many of you know my story, and you know that I was not punished by my church."

Her "story" is, we believe, that she herself recently had medical treatment. In 2001, she told me she was getting chemotherapy and radiation treatment for cancer and that the Christian Science church did not punish her for it.

The child she lost "under medical treatment" was an infant born prematurely in Puerto Rico. The hospital did not have a neonatal intensive care unit. It seemed to us that the infant more likely died not because of medical treatment, but rather because not enough medical treatment was available.

Many spiritual healings described

The last witness was lifelong Christian Scientist Kimberly Furbish (*sic*?) of Des Moines. She testified that Christian Science had healed her of "virulent" pneumonia, fevers, earaches, and stomach cancer. Also, she broke her foot "completely in half," and Christian Science healed her in three days.

She claimed that Christian Science had healed her child of spinal meningitis, "red eye," sprained ankle, and flu. Her son "split open his head" while playing tennis. "His coaches were amazed" at his healing through Christian Science—"our system of health care," she said.

CHILD replies

Afterwards CHILD circulated to the legislators our comments on the opponents' testimony. "We all agree," CHILD wrote, "that DHS can take action to protect children when the DHS learns of harms to children. We need HF368 so that parents themselves have a duty to get medical care for children in case DHS does not learn of the risk to the child."

Church policy not valid argument for exemption

As for whether the Christian Science church prohibits its members from getting medical care, that "should be a non-issue to legislators," CHILD said. "The fact is that the Christian Scientists got, and want to keep, a law that allows them to deprive a child of lifesaving medical care. Mrs. Gregory has obtained medical treatment to save her own life, but thinks she should have a legal right to deprive a child of the chance to live."

No diagnosis or accountability

None of the spiritual healings narrated at the hearing, CHILD pointed out, were medically diagnosed though the Christian Scientists called their methods "health care."

CHILD's letter continued:

Medical practice is a state-licensed system accountable to its patients and the state. Its successses and failures are public information. The medical profession is obligated to select treatments which scientific data shows to be effective and to alter treatments in response to data.

In contrast, the Christian Science church has never provided data to indicate that their

treatments heal serious diseases of children, such as type 1 diabetes or bacterial meningitis, for example.

What the opponents call "health care" simply does not have anything remotely resembling the accountability and responsibility required of the medical profession.

Iowa's child endangerment law requires parents to provide "necessary health care" for children. Parents can call all sorts of things "health care" and are free to provide them as long as they provide, in addition, the health care that is "necessary" to prevent "substantial harm" to the child.

Iowa should not have a law exempting any parents from the duty to provide necessary health care.

"You will be successful eventually"

A week later the subcommittee chairman, Rod Roberts, met with us. He said the subcommittee had decided the bill did not belong in the Education Committee and would ask the House Speaker to reassign it.

"I'm sure you will be successful eventually because you are going about this in the right way," he added.

In all our contacts he expressed a lot of respect for our work, but when we asked him point-blank if he would vote for the bill, he did not answer.

The bill was then assigned to the House Judiciary Committee, chaired by Kraig Paulsen, who was also on the Education subcommittee and had heard all the testimony at the hearing.

We stayed in Des Moines and met with all but two members of House Judiciary. We believe a majority would have voted for the bill.

Dannemann and other Maharishis flooded the legislature with sensational allegations against us. They distributed a newspaper at the Statehouse, *Lights On at the Capitol*, with an article on the "Mission of Rita Swan."

Maharishi blasts Speaker's "proclivities"

Dannemann wrote House Speaker Christopher Rants:

It is known that you and Ms. Rita Swan are working this bill being together as members of the same Methodist Church. We will not tolerate back room deals and personal proclivities. This is a government for the people, by the people and of the people. HF 368 is unconstitutional and your position not to defend the Constitution violates your oath of office, which is, I might point out, a legal document. The Supreme Court has always upheld religious freedom....

There is no room for personal or emotional interpretations like that offered by Rita Swan, Ms. Basu of the Des Moines Register, yourself or Representative Kevin McCarthy. It is surprising to me that Rep. McCarthy, who should know better as he is an attorney, does not recourse to the Constitution of which his oath of office requires him to defend....

The need to protect the right to free and unfettered exercise of one's personal spiritual beliefs is the initiating impulse of our democracy. You hold the very kernel of democracy in your hand. Are you going to crush it or plant it?

While Maharishis expended vitriol and energy against HF368, their main goal seemed to be getting a bill passed that allowed unlicensed providers to diagnose disease and treat it with non-drug remedies, but have no accountability for harms. Their bill was killed in committee, and then Dannemann became even more shrill with e-mails accusing legislators of "pranc[ing] around with Rita Swan" instead of listening to her "experts."

The Christian Scientists' many e-mails to legislators were far more civil, though in our view no more logical. One legislator told us their two main points were that Christian Science heals disease and gives parents freedom to choose medical care.

The following organizations and offices endorsed HF368:

Law and law enforcement

Attorney General

Iowa State Bar Association Health Law Section Iowa County Attorneys Association Youth Law Center

Medical

Iowa Medical Society

Iowa Chapter of the American Academy of Pediatrics Iowa Academy of Family Physicians Iowa Chapter of the American College of Emergency Physicians Iowa Nurses Association Iowa Association of Nurse Practitioners Iowa Nurse Practitioners Society Healthy Siouxland Initiative

Religious

Iowa Catholic Conference Iowa Conference of the United Methodist Church Lutheran Services in Iowa Ecumenical Advocates

Other Child Advocacy

Prevent Child Abuse Iowa Iowa Parent-Teacher Association Children's Healthcare Is a Legal Duty

Rekha Basu had an excellent op-ed column about CHILD's work in *The Des Moines Register* on February 17.

None of that mattered to Representative Kraig Paulsen, however. He appointed himself chair of the subcommittee and put another Republican opponent on it, passing over the two Republican committee members who were co-sponsoring the bill.

Later he told us he was chairing the subcommittee because he "was not at peace with the bill" and intended to kill it.

Chairman opposes "necessary health care" standard

Paulsen said he could "see" requiring parents to get medical care in cases of "traumatic injury," but not in "marginal cases like pneumonia."

We pointed out that the bill required parents only to get "necessary health care" when they were aware that the child was seriously ill or injured.

"But," Paulsen countered, "who decides what is necessary?"

We replied that Iowa's child endangerment law already defines the requirement for most parents as the health care necessary to prevent substantial harm.

Paulsen's mind was made up, however.

5,650 miles

Paulsen's decision to kill the bill without allowing a committee vote was a severe disappointment to us. Doug and I expended as much energy as we possibly could for a successful outcome this session. We've been working off and on since 1985 for equal rights of Iowa's children to health care.

In the 2005-06 session we felt we had finally learned what we needed to know about Iowa's legislative process to succeed. We drove more than 5,650 miles around the state meeting with legislators in their home districts and working at the Statehouse. We held lunches for the interest groups. We were thrilled that so many organizations endorsed the bill and registered their lobbyists as supporters of it.

Court rulings don't interest Judiciary Chair

When we first contacted Paulsen in October for a meeting, he asked for evidence that the bill was constitutional. I asked if he would consider *American Law Reports* a credible source on the question. He said he would, so we brought him "Parents' criminal liability for failure to provide medical attention to their children" in 118 *ALR*5th 253-345. It opens with this statement: "It is generally recognized that parents have a duty to provide medical attention to their children. Violation of this duty can lead to criminal charges against the parent." The article cites many court rulings in which parents have been held responsible for failure to provide medical care, including several of parents with religious objections to medical care.

We gave him several other law review articles and court rulings during the session in Des Moines. When we asked him if any of it had impressed him, he said vaguely that "some of it did," but that what made him decide against the bill was the subcommittee hearing. The Maharishis and Christian Scientists were more persuasive with him than the bill supporters, legal arguments, or court rulings.

Two weeks later Paulsen told McCarthy that he thought it was unconstitutional to require parents with religious beliefs against medical care to provide medical care for children. He thought so in October and even though we gave him many rulings that it is constitutional, and even though he had no case law indicating that it is unconstitutional, he still thought so in March.

Should any parents have to get medical care?

Indeed, from what Paulsen told us, we gather that he does not think any parents should be required to get medical care for children unless blood is gushing out from a "traumatic injury."

It seems like a simple matter of equal protection and non-discrimination to us. We are not asking for a radical, novel standard. The vast majority of Iowa parents have long been required to provide the health care necessary to prevent substantial harm to a child.

Ironically, despite all our hard work since 1985, the only religious exemption the Iowa legislature has repealed or modified was removed with no debate or discussion—probably because the bill sponsor did not notice what he was doing.

Nebraska legislature rejects bill for religious exemption

For the second time in recent years, a bill was introduced in Nebraska to allow religious exemptions from metabolic testing of newborns. Again this session, the exemption bill died in committee.

In February a hearing was held before the Unicameral's Health and Human Services Committee. Governor Heinemann prohibited members of his administration, including those in charge of the metabolic screening program, from taking a position on the bill or even attending the hearing. The program director had to stay in her office and be ready to answer any legislator's questions by phone.

Screening prevents catastrophic damage

Many opponents gave powerful testimony against the bill. A woman whose son was born with phenylketonuria in another state and didn't get treatment in time testified about the heartbreak of a child's preventable mental retardation. Another woman testified that two of her sons were born in Nebraska with galactosemia that was detected in time and therefore the boys are alive and healthy today. Two physicians testified, including the indefatigable Dr. H. E. Wiltsie, an Omaha pediatrician who has been an expert witness in all the court cases over metabolic screening.

Two Omaha parents with religious objections to the screening testified that they should be allowed to practice their religion and that metabolic disorders were rare. They complained that they had to drive across the Missouri River into Iowa to give birth so they would not be required to have their baby tested for metabolic disorders.

Four CHILD members attended the hearing. Two testified about growing up in Christian Science households and how metabolic disorders affected their families. Nebraska CHILD member Janice Soderquist's testimony is reprinted below followed by that of CHILD founder Rita Swan.

CS parents refuse to put baby on diet for pku



"Chairman Jenson and members of the Health and Human Services Committee, I am Janice Soderquist. I live in Axtell and am a constituent of Senator Johnson.

"I urge you to vote against LB1104 and maintain Nebraska's requirement of metabolic screening for all babies. A

parent's religious belief should not give him or her the right to deprive a child of medical care.

"I grew up in a Christian Science household. I was eighteen when my sister was born in 1966. Although Christian Science opposes medical care, it allows women to have babies in hospitals. I could tell when my mother and sister came home from the hospital, that something was wrong. My grandmother and parents looked very worried. A doctor was calling our home. Nobody would tell me what was wrong. I was frightened.

"Finally, my grandmother told me that my sister had tested positive for phenylketonuria. Because of their religious beliefs, my parents refused to put my sister on the diet needed to prevent the damage from this terrible disease. Back in those days, the state did not follow up with our family. "Fortunately, the test must have been a false positive because my sister developed normally without the diet. To my mother and grandmother, this was a great victory for Christian Science, but it looks to me now like Russian roulette and a very foolish risk to take with a child's life."

Swan's testimony

"CHILD urges Nebraska not to enact a religious exemption to metabolic screening. All babies deserve the benefit of detecting metabolic disorders in time to prevent the lifelong catastrophic damage they will inflict if left untreated.

"Nebraska has required metabolic screening without a religious exemption since 1983. The screening program director and an Omaha physician who specializes in metabolic disorders believe that Nebraska has not missed a baby with a metabolic disorder since 1973. That's an excellent record, and we hope the legislature will keep it that way.

"In 2003 parents of an Omaha baby refused to have their baby screened because of their religious beliefs against withdrawing blood. The Douglas County prosecutor filed charges against the parents. The district court ruled that the state had a right to require the test.

"CHILD, Inc. filed an amicus brief in support of Nebraska when the case reached the Nebraska Supreme Court. It was co-signed by the Nebraska Chapter of the American Academy of Pediatrics and National Association of Counsel for Children.

"We pointed out that the U.S. Supreme Court has never held that parents have a constitutional right to an exemption from state laws protecting their children's health. More than sixty years ago the High Court ruled that our First Amendment "right to practice religion freely" does not include a right to neglect or endanger a child's health and that it is in "the interest of youth itself, and of the whole community, that children be both safeguarded from abuses and given opportunities for growth into free and independent well-developed men and citizens." *Prince v. Mass.*, 321 U.S. 158 (1944)

Screening is only way to prevent damage

"The Omaha parents argued that the state did not have the right to interfere with a parent's religious practice until the child was actually sick. "Child advocates point out, however, that the metabolic screening is necessary in order to know if the child has a metabolic disorder. These disorders typically do not show clinically observable symptoms in time for effective treatment. A mother's metabolism corrects that of the foetus, so the baby is born apparently normal. After birth, however, metabolic poisons accumulate, brain growth retards, and brain damage may ensue. Yet it might be years before this damage is seen. Some babies will seem fine when unstressed, but even minor to moderate stress, such as from a cold, can cause a metabolic crisis that leads to serious illness or sudden death.

"The metabolic screening is a very small intrusion into family privacy. Only a few drops of blood are needed to test for all the diseases listed in Nebraska's law. Often the treatment consists only of dietary manipulation. These simple measures prevent the terrible damage inflicted by these diseases, including mental retardation, growth retardation, failure to thrive, liver disease, and sudden death.

"The Nebraska Supreme Court unanimously upheld the state's right to require metabolic screening without a religious exemption. The U.S. Supreme Court declined to review the ruling. Our brief and the ruling can be seen at our webpage at www.childrenshealthcare.org.

Early detection critical

"Now the state is being sued in federal court by members of the Church of Scientology, whose religion opposes doing the test in the baby's first week of life. But there are good reasons that Nebraska requires the test to be done when the baby is between 24 and 48 hours old. Georgia parents lost their baby to galactosemia when he was nine days old because the metabolic screening was not done soon enough in 1998. They founded an organization to better protect babies from metabolic disorders at www.savebabies.org.

Nebraska values all children equally

"Nebraska is the only state that has never had a religious exemption to child abuse or neglect charges. Nebraska is one of four states that require metabolic screening of all babies. We think you should be proud of your laws for valuing all children equally. "I'm ashamed to say that Iowa, the state I live in, has a religious defense to manslaughter. Parents are allowed to let a child die if they have religious beliefs against medical care. Delaware has a religious defense to first-degree murder, and Arkansas has a religious defense to capital murder. Two states have laws giving a religious exemption from bicycle helmets for children. Our country has well over a thousand religious denominations. While people have absolute freedom to believe whatever they wish, we should limit religious practices that compromise others' rights.

Nebraska's state motto is "equality before the law." Please do not discriminate against a group of children by depriving them of protections you extend to others. Please vote against LB1104.

Maine psychiatrist sees child protection in new law

CHILD received the letter below from Dr. Owen Buck, a psychiatrist in Lewiston, Maine, about the legislation, LD482, he and other Maine CHILD members worked so hard for. The bill, as amended and enacted, states that a caregiver commits the crime of child endangerment when s/he "knowingly deprives the child of necessary health care, with the result that the child is placed in danger of serious harm," but, to our dismay, retained the caveat that a person who provides "treatment for a child. . . by spiritual means through prayer may not for that reason alone be deemed to have knowingly endangered the welfare of that child." 17-A Maine Rev. Statutes § 554 and 557.

Buck's letter refers to Anne Wold, the Christian Science lobbyist; Everet Fowle, president of the Maine prosecutors' association; and Ben Dudley, the lead bill sponsor. DHHS is the state Department of Health and Human Services. "From away" refers to the Christian Science effort to brand several of us as outsiders.

Dr. Buck writes:

"I wanted to comment on your assessment of the outcome on LD482, which appeared in the latest issue of the CHILD newsletter [#4, 2005]. "I think that you are unduly pessimistic about the standard enacted, of 'knowingly' failing to provide 'necessary health care.' Of course, at the end of the day it doesn't matter what you or I think, or what Ms. Wold or Mr. Fowle think. What will matter is what the judge and/or jury will think at some point in the future if/when the case of a child, dead or injured because of the 'radical reliance' of the Christian Science belief system, comes to legal attention.

"If such a case occurs, it would be prima facie evidence that the CS method had been unsuccessful. It would be an easy task for the prosecutor to introduce evidence (placebo-controlled double-blind studies) that effective medical treatment for the condition existed. The failure of the CS method should render the scientifically proven method to become 'necessary health care.' I can't imagine a jury finding otherwise (but of course you never know). Furthermore, it would be most difficult for an accused to successfully argue that he or she did not 'know' that there was a medical care system outside of the CS community, and therefore is protected from prosecution.

"While the 'from away' factor was certainly part of the reason we did not achieve more, I think that far and away the most important factor was the lack of an index case. Because there was no index case, the legislators and the DHHS had little desire to stir up a controversy. They had many other bigger fish to fry. Mr. Dudley, once he realized that his bill was not going to be a walk-through, was interested in getting the matter settled with as little fuss as possible. All things considered, I think that we achieved a reasonable good outcome."

Texas baby's death and burial not reported because of religious beliefs

We know that a one-month-old baby boy died July 7 in or near Abilene, Texas, but only because an anonymous caller reported to state Child Protective Services a week later.

Police questioned his parents, who are married and live in Abilene, for hours, but the father refused to disclose where he had buried the baby. Later, the Neither the baby's birth, death, nor burial was reported to the state. The father told police that he and his wife did not inform the state of the baby's death or burial because of their religious beliefs.

The police declined to give the names of the family or their religion.

Parents deny baby suffered trauma

The parents said the boy was not feeling well, so they took him for a ride in a car. At some point, the boy stopped breathing.

A preliminary autopsy showed the baby died of traumatic asphyxiation, a sudden or severe compression of the chest or upper abdomen that prevents breathing.

The Tarrant County Medical Examiner's office is doing a complete autopsy.

Religious beliefs are not a viable defense for any kind of criminal conduct in Texas, Taylor County District Attorney James Eidson said.

Religious defense to felony abuse and neglect

Unfortunately, that is not completely true. More than a decade ago the Christian Science church got a religious exemption to criminal abuse and neglect enacted in Texas, stating:

It is an affirmative defense to criminal injury to a child that the act or omission was based on treatment in accordance with the tenets and practices of a recognized religious method of healing with a generally accepted record of efficacy. Texas Penal Code 22.04(k)

In other states, the church has argued that its third-party reimbursements from the insurance industry, statutory religious exemptions around the country, and thousands of testimonials constitute a generally accepted record of effectiveness.

Taken in part from the *Abilene Reporter-News*, July 15.

Judge orders church midwife to stop delivering babies

In August a judge ordered a member of the Church of the Firstborn to stop assisting in delivery of babies.

Premature, breech birth: no medical care

Doris White, 73, was charged last year with unlawful practice of midwifery after she helped deliver a baby near Martinsville, Indiana. Sarah Leeman was born breech and two months premature on May 28. She weighed less than three pounds.

As members of the Church of the Firstborn, her parents, Louis and Patricia Leeman, chose a home delivery and withheld medical attention from their struggling baby.

On June 4, someone called for help for a baby "having difficulty breathing." When emergency workers arrived, Sarah was not breathing. An autopsy determined she had died of bacterial meningitis.

The Leemans had another baby who died in July, 2002. A death certificate states the baby was stillborn at their home. No autopsy was done.

The Leemans were not charged in either death.

White expressed bewilderment at the charges against her. She said she had delivered over a hundred babies and had filled out birth certificates at the board of health. No one complained before about her delivering babies.

Church members knew baby was sick

White said she knew when Sarah was born that "it would take God's intervention for the baby to survive." Church members came to the home to pray for the baby; one stayed in the Leeman home through the night.

Medical experts testified to a grand jury that Sarah would have had a 98% chance of survival if she had been seen by medical professionals and treated with antibiotics, Morgan County Prosecutor Steve Sonnega said.

Instead of taking the charge against White to trial, Sonnega asked for an injunction. Morgan County Superior Court Judge G. Thomas Gray issued a permanent injunction barring White from practicing midwifery.

Midwife refuses to obey court order

White told the judge that she had been called by God to become a midwife and could not promise to obey the injunction.

Judge Gray warned she could be found in contempt of court if she violated the injunction.

White replied quietly, "If I'm called [to deliver a baby], I'll go."

Legislature ignores grand jury recommendations

The grand jury that indicted White made the following recommendations for state law:

- require all babies born at home to be seen by a qualified medical care provider within 24 hours of birth if the infant is born prematurely or weighs less than five pounds
- require immunizations for all children before age 5
- require a well-baby certificate for infants born at home within 48 hours, in addition to a birth certificate, with a fine imposed if this is not done in a timely manner
- clarify the definition of midwifery.

No legislator sponsored any of these proposals. Indiana law requires that a midwife be a registered nurse and graduate from an approved midwifery school. Presently, Indiana has no approved schools.

Taken in part from *The Indianapolis Star*, Aug. 19, and *Morgan County Reporter-Times*, August 16. See also the CHILD newsletter #3, 2005.

Mumps epidemic in Iowa exposes religious concerns

A mumps epidemic began in Iowa early in 2006 and then spread to several more Midwestern states. The disease was first seen at a college in Dubuque and may have been brought by students returning from England, where mumps is endemic.

By mid-August Iowa had had 1631 laboratoryconfirmed cases of mumps and 313 probable cases. Vaccination status of 30% of the infected persons was unknown. Another 7% had not received any doses of measles/mumps/rubella (MMR) vaccine, and 14% had received only one dose.

877 persons, 49% of the total, had received two doses of MMR vaccine but still got mumps since the vaccine is only 95% effective.

Abortion connection criticized

Pro-life leaders raised concerns that the rubella component of the combination vaccine was "made from aborted fetal tissue." The Christian Medical and Dental Association, Catholic Medical Association, and Children of God for Life all criticized the rubella vaccine and urged pharmaceutical companies and the U.S. government to develop a vaccine with no connection to abortion.

No more fetal tissue used today

Tissue from aborted human fetuses was used to develop vaccines against rubella, hepatitis A, rabies, and varicella (chickenpox). The abortions were done legally in the 1960s and were not done for the purpose of vaccine research.

Cell-line cultures were developed from the original fetal tissue. No more fetal tissue is needed to make vaccines. The vaccine manufacturers obtain human cell lines from cell banks certified by the Food and Drug Administration.

In the midst of the mumps outbreak, the Dubuque County Right to Life's executive director urged people to get vaccinated only against mumps. She said rubella has been "virtually eradicated" and therefore it is no longer necessary to be vaccinated against it.

Vatican: protecting children and public from infectious disease is more important

However, the Archdiocese of Dubuque issued a statement supporting the Iowa Department of Public Health's position that vaccination against rubella was still necessary. At present, the U.S. does not have an alternative to its rubella vaccine made from human cell lines, and, therefore, the archdiocese said, Catholics are permitted to use the MMR vaccine on a temporary basis.

In June, 2005, the Vatican Pontifical Academy for Life released the statement "Moral reflections on

vaccines produced from cells derived from aborted human fetuses." It declared that parents and doctors have only a remote connection to the abortions and this is outweighed by the importance of protecting children and the entire population from diseases.

Rubella vaccine prevents abortions and deformities

The Vatican pointed out that vaccination against rubella is particularly important in preventing abortions and catastrophic deformities of infants:

When a woman catches the infection during pregnancy, especially during the first trimester, the risk of foetal infection is very high (approximately 95%). The virus replicates itself in the placenta and infects the foetus, causing the constellation of abnormalities denoted by the name of Congenital Rubella Syndrome. For example, the severe epidemic of German measles which affected a huge part of the United States in 1964 thus caused 20,000 cases of congenital rubella syndrome, resulting in 11,250 abortions (spontaneous or surgical), 2,100 neonatal deaths, 11,600 cases of deafness, 3,580 cases of blindness, [and] 1,800 cases of mental retardation.

Without vaccination, it would be nearly impossible for pregnant women to be assured of avoiding exposure to rubella. The virus is very common and, even though it severely damages embryos and fetuses, 50% of those infected as babies manifest no symptoms of the disease, the Vatican said.

"The severity of congenital rubella and the handicaps which it causes justify systematic vaccination against such a sickness," the church said.

Drug companies "immoral"

Nevertheless, the Vatican labeled the pharmaceutical industries "immoral" for producing vaccines made from human cell lines:

It is up to the faithful and citizens of upright conscience (fathers of families, doctors, etc.) to oppose, even by making an objection of conscience, the ever more widespread attacks against life and the "culture of death" which underlies them. . . . The use of such vaccines contributes in the creation of a generalized social consensus to the operation of the pharmaceutical industries which produce them in an immoral way.

Therefore, doctors and fathers of families have a duty to take recourse to alternative vaccines (if they exist), putting pressure on the political authorities and health systems so that other vaccines without moral problems become available.

"There remains," concluded the Vatican, "a moral duty to continue to fight and to employ every lawful means in order to make life difficult for the pharmaceutical industries which act unscrupulously and unethically. However, the burden of this important battle cannot and must not fall on innocent children and on the health situation of the population—especially with regard to pregnant women."

The Takahashi vaccine against rubella and the Aimmugen vaccine against hepatitis A are manufactured in Japan without use of human cell lines. Their safety and effectiveness have not been adequately tested in the United States.

Taken in part from *Dubuque Telegraph-Herald*, April 11, 25, and 26, and the Vatican statement.

Vaccine-preventable disease among the Amish

The August 4th issue of the *Mortality and Morbidity Weekly Report* reports on a pertussis (whooping cough) outbreak in a Delaware Amish community that extended from September 2004 through February 2005.

An Amish community of 1711 persons in Kent County, Delaware, had 345 cases of pertussis during that period, primarily among its preschool children.

Extremely low vaccination rates

The Delaware Division of Public Health (DPH) sent questionnaires about symptoms to the 323 households in the Amish community. 184 returned them, and officials from the Centers for Disease Control and DPH interviewed the 110 families in which pertussis was suspected.



Amish Farmer Credit: Ottumwa Courier

Of 123 patients aged 6 months-5 years living in interviewed households, 88 (72%) had no records of vaccination with diphtheria-tetanus-pertussis (DTP/DTaP) vaccine, six (5%) had records of receiving 1 or 2 doses, and 29 (24%) had records of receiving \geq 3 doses. For 163 children aged 6 months-5 years without clinical pertussis residing in households with pertussis patients, 106 (65%) had no records of vaccination with DTP/DTaP vaccine, eight (5%) had records of receiving 1 or 2 doses, and 49 (30%) had records of receiving \geq 3 doses.

Of the 96 households interviewed that had pertussis cases, a total of 43 (45%) reported not vaccinating any children in their household, 40 (42%) households reported vaccinating at least some children, and 13 (14%) did not provide this information.

Religious objections not given

Of the 43 households not vaccinating children, 19 cited "fear of side effects" as the reason, 13 reported that they "didn't think about it," and 11 did not provide specific reasons for non-vaccination. Of the 40 respondents who reported that their children had received vaccinations, 29 (64%) reported vaccination at vaccine clinics set up at Amish homes by DPH nurses.

No hospitalizations or deaths were reported. Medical treatment with erythromycin was accepted by 51% of persons in households with pertussis cases.

The Amish have had many other outbreaks of vaccine-preventable disease because of not immunizing their children. Indeed, Ruth Garrett, who grew up in the Amish community in Kalona, Iowa, writes that "every year in Amish schools across the country there are uncontrolled outbreaks of disease."

In 2005 there were five cases of polio among the Amish in Minnesota. In 1991 there were at least 890 cases of rubella among the Amish in five states and more than a dozen Amish babies born with the devastating congenital rubella syndrome in Pennsylvania alone.

16% vs. 95%; one death reported

Between December 1999 and February 2000, eight cases of invasive *Haemophilus influenzae* type b (Hib) disease in children under six years old were identified in Pennsylvania. None of the case patients had been vaccinated. One of the children died. Six of the eight cases occurred in two Amish communities. None had an underlying illness that put him or her at higher risk for Hib disease.

All the Amish children were older than six months and therefore old enough to have received three doses of Hib vaccine. The non-Amish children were under two months old. One of them lived with 3- and 5-year-old siblings who were not vaccinated.

Only 16% of the Amish children were fully vaccinated as appropriate for their age compared to 95% of children in a nearby non-Amish community.

Religious and other beliefs cited by 30%

Of 51 Amish parents interviewed as to why they did not give their children the Hib vaccine, 6% cited religious objections, 24% cited philosophical objections, and 51% said vaccination was not a priority to them compared to their other obligations. Others said the vaccine was too expensive or it was too difficult for them to travel to a public health clinic.

Nineteen of the 51 parents said they now planned to have their children vaccinated against Hib. When asked what had changed their minds, many cited the outbreak in their communities.

Why Amish vaccination rates remain low

Though the Amish interviewed in Delaware did not voice religious opposition to immunization and only a minority of the Amish interviewed in Pennsylvania cited religious or philosophical objections, vaccination rates remain very low in many Amish communities. The Amish practice separation from the world through group solidarity and caring for their own. They tend to define illness in terms of failure to function in the work role rather than of symptoms. They regard education beyond eighth grade as a threat to their way of life. These factors lead to delays in seeking medical treatment and disinterest in preventive measures.

In 1986 an article in *Nurse Practitioner* reported that Amish men outlive Amish women in part because of the high Amish birthrate of seven live births per woman. Birth control and abortion are forbidden by religious doctrine even when pregnancy is life-threatening, they said. The burden of raising large families without electricity, cars, and other modern conveniences may be another reason preventive medicine is not a "priority" for many of the Amish.

The *MMWR* authors recommend promoting "vaccination in Amish communities through culturally appropriate strategies, such as education and outreach to community leaders."

Taken from P. Eggers, D. Austin et al., "Pertussis Outbreak in an Amish Community-Kent County, Delaware, September 2004-February 2005, MMWR 55 (Aug. 4, 2006):817-21; Edward Friedlander, "Opposition to Immunization: a Pattern of Deception," Scientific Review of Alternative Medicine 5(2001):18-23; A. Fry, P. Lurie et al., "Haemophilus influenzae Type b Disease Among Amish Children in Pennsylvania: Reasons for Persistent Disease," Pediatrics 108 (Oct. 2001):e60; Ruth Irene Garrett, Crossing Over: One Woman's Exodus from Amish Life (Allen, Texas: Thomas More, 2001):169; and C. Adams and M. Leverland, "The Effects of Religious Beliefs on Health Care Practices of the Amish," Nurse Practitioner 11 (1986):58, 63, 67.

Amish diet implicated in baby's protein malnutrition

In the article "A rapidly deteriorating baby girl: can you judge this book by its cover," two doctors describe a six-month-old Amish girl who was ultimately diagnosed with kwashiorkor or protein malnutrition and severe dehydration after an extensive medical workup.

After being weaned, the baby was fed canned cream diluted with boiled water and some sugar added, a common practice in her Amish community. Her only other nutrition was tea with sugar and occasional cod liver oil. Canned cream is very high in fat, but has no protein or carbohydrates.

The baby recovered after care in two hospitals and has done well at home, but will likely always be small for her age.

The doctors say the case is a warning to "be wary when a sick infant has an unusual diet even if she appears well nourished" and be aware that protein malnutrition does occur in the United States. Taken from Jennifer Twente and Richard Strauss, "A rapidly deteriorating baby girl: can you judge this book by its cover?," *Contemporary Pediatrics* 22 (June 2005):18-22,72.

About CHILD, Inc.

CHILD is a national membership organization dedicated to the welfare of children, particularly when religious beliefs, cultural traditions, or quackery lead to child abuse or neglect. CHILD provides research, public education, amicus briefs, and a support group for ex-Christian Scientists. CHILD lobbies for equal protection of children within its tax-exempt limits. CHILD is a member of the National Child Abuse Coalition.

For more information on CHILD and a membership application form, visit our web page at www.childrenshealthcare.org. To reach CHILD by mail, phone, fax, or e-mail, see the contact information on page 1.