

Children's Healthcare Is a Legal Duty, Inc.

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Equal rights for children under the law



Matthew Douglas Swan
1976-1977

Thirty years and counting

CHILD was founded in 1983, so in this issue we're taking a look back at the thirty plus years of its existence and our family's journey building up to its founding.

In 1977 Doug and I lost our only son Matthew because of trusting Christian Science practitioners to heal him. Our experience is described in my memoir, *The Last Strawberry*, available at www.hagsheadpress.com and www.childrenshealthcare.org.

We left the Christian Science church immediately after his death and within a year decided that harm to children from faith healing should be a public issue. I made several attempts to get the print media to cover Matthew's death. Newspapers would not touch it even as a letter to the editor. The editor for the newspaper where we lived said my

letter "was very far out of line and could get [them] in a lot of trouble.

In 1978 we moved to North Dakota and had a baby daughter. 1979 was International Year of the Child. I promised myself on New Year's Day that I would do something every day that year to bring Matthew's death to public attention. I got rejection slips from popular magazines and didn't know where to find the fledgling child protection organizations. I was nursing a baby in a North Dakota farmhouse and had no computer.

In the late summer I read about a group of women attorneys meeting in Albuquerque to discuss child abuse. I asked to speak to them. The woman in charge said grudgingly that I could speak at their gathering for ten minutes but should be aware in advance that most of the participants would disagree with me. I planned to drive there and do that.

An hour on national television

In September I decided to try the broadcast media and wrote *Phil Donahue*. A producer called immediately and we became Donahue's only guests for an hour on national television because the Christian Science church refused to face us. We were the first persons to speak voluntarily and publicly about the loss of a child because of Christian Science, and we still are the only ones to do so.

We received over 600 letters from the Donahue viewers. Several asked us to establish a charitable organization so they could donate to it. Our whole family suggested various names with "clever" acronyms such as Prevent Religiously-Oriented Deaths (PROD). That one is so bad I must not be remembering it correctly.

We eventually decided it was better to say what you are for than what you are against and arrived at Children's Healthcare Is a Legal Duty (CHILD).

Unfortunately the name is a whole sentence, and, though I hoped “health care” would evolve to be one word in the dictionary, it never did, so we’ve been guilty of promulgating bad grammar for thirty years. This bothers me, but we still like the name. CHILD was incorporated in Iowa in February, 1983.



Rita and Doug in the 1980s.

Backtracking to our pre-CHILD activities, we filed the nation’s first wrongful death suit against the Christian Science church and its practitioners in 1980. Our complaint charged that they had breached duties they owed to Matthew and us.

Pioneering attorneys

We were represented *pro bono* by Charfoos and Christiansen in Detroit. Sharon Lutz and other attorneys in the firm spent thousands of hours on our case and also gave emotional support to grieving parents.

The attorneys had little beyond the facts of our case to draw on. They searched through databases and found nothing had been written about Christian Science children in the medical literature. They tried to take out an ad in the *Boston Globe* soliciting information about Christian Science care and treatment of children, but the *Globe* refused to run the ad. (The church is headquartered in Boston.) As discussed in my memoir, our case was dismissed without being allowed a trial.

Religious exemption laws

When Matthew was dying in a hospital, Michigan’s public relations manager for the church told us, “You won’t be prosecuted.” My silent reaction was, “His priorities are not our priorities.” When Matthew was sick we hadn’t thought about the laws; we were too terrified and too focused on obeying the practitioners to get a healing for him. But later I remembered the manager testifying in church about a Michigan law he had gotten to protect the “right” of parents to rely on Christian

Science to heal their children. I found the law and asked public officials what it meant. They were unsure, but one exclaimed, “Surely we don’t have a law making Christian Science children second-class citizens.”

By writing to social service departments in every state, we slowly learned that many states had identical laws. One state official finally told us

the federal government required states to enact religious exemptions to child neglect in order to get federal funding for child protection programs.

Years of protest letters and trips to DC

Doug and I made several trips to Washington and wrote scores of letters protesting the religious exemption mandate. Federal officials admitted that the Christian Science church was the only party that had asked for the policy.

In 1980 the U.S. Department of Health and Human Services issued new proposed regulations maintaining the mandate and going out of their way to point out that states did not have to include medical care as a parental duty in their laws. Only food, clothing, and shelter were required. HHS left all parents free to deny children medical care for any or no reason.

Feds clueless

Also in 1980 they issued a booklet entitled “Child Abuse and Neglect: State Reporting Laws,” which included this statement: “The religious immunity or spiritual healing exemption has been the subject of widespread legislative activity. . . . Despite some commentators’ characterization of these clauses as an impediment to the protection of children, legislative adoption of the clause has increased from 11 jurisdictions in 1974 to 44 jurisdictions today.” (p. 14)

For some reason, the Department never explained why states had been so busy adopting those religious immunity laws after 1974.

HHS drops mandate, adds medical care reg

Finally the director of the National Center on Child Abuse and Neglect, told us HHS would drop the policy because of our protest and because lawyers had advised them HHS was arguably in violation of the Establishment Clause, which prohibits the government from favoring one religion over another.

In 1983 HHS did indeed rescind the requirement and even added a regulation that states in the federal grant program must include failure to provide medical care in their definitions of child neglect.

States allowed to keep religious exemptions

They did not, however, require the states to change their religious exemptions and by 1983 the damage was done. By then every state except Nebraska had a religious exemption to neglect in either the civil or criminal codes. Several states met the federal requirement by enacting laws that explicitly exempted only Christian Scientists.

Because of these religious exemptions public officials have ignored deaths of hundreds of children in faith-healing sects. In our view the Christian Science church bears some moral responsibility for all of the deaths.

First victory: South Dakota

We have been left with the Herculean task of getting these religious exemptions repealed so that children have equal protection of the law. Our first victory was in South Dakota in 1990. Five babies had died there in the anti-medical sect Endtime Ministries. One of the bereaved mothers, a pastor, and I drove hundreds of miles to Pierre to testify. After an initial committee hearing the chairman took all our materials for study. At the second hearing the chairman proposed a bill that he declared “no reasonable person” could object to. We immediately agreed to accept it because it repealed five religious exemptions. With public TV cameras clicking away, the Christian Science lobbyist was silent for a long time, but finally said, “I think we can live with it.”

In the hallway a lawyer whispered to us to get the bill voted on before the church changed its mind and sure enough by Monday, the lobbyist—

probably after his Boston handlers talked to him—opposed the bill.

“Oh, but we had a deal,” we said. Deals make life much simpler for legislators, and the bill sailed through.

Unfortunately, we discovered years later that South Dakota had originally had two religious exemptions to non-support and we got only one repealed. Our members have tried at least twice to repeal the remaining one but have not succeeded.

Seven-year struggle in Ohio

We worked for seven years in Ohio because we had several dedicated members there, because Ohio had faith deaths, and because the laws were above-average bad. They included a law stating that “no report” to Child Protection Services was required on a child deprived of medical care for religious reasons and another giving a religious defense to felony child endangerment and manslaughter.

Feds: exemptions violate federal policy

In 1987 we received help from an unexpected source: the federal government advised Ohio that its religious exemptions in the civil code violated federal regulations. HHS took the position that the regulations permitted a religious exemption only from adjudicating a parent as negligent but that it could not be an exemption from a duty to report, from investigating a case, or from providing court-ordered services to the child. Ohio was given over a year to change its religious exemption but did not get it done, in part because the Ohio lobbyist for the Christian Science church made trips to Washington and came back telling state legislators he had gotten HHS to drop or modify its ultimatum.

This was not true and in 1988 HHS withheld \$750,000 in child protection money for Ohio and gave it to other states.

Every seat taken

The Ohio legislature held marathon hearings over five weeks on our bill to repeal religious exemptions in the civil and criminal codes. The church bussed Christian Scientists in from around the state who wore American flags in their lapels and took up every seat in the hearing rooms. I remember one well-dressed TV reporter crawling in on her hands and knees.

Religious defense ruled unconstitutional

During our seven-year struggle criminal charges were filed in two Ohio counties against parents who let their children die without medical care and relied on prayer and ritual instead. Both the prosecutor and the parents challenged the religious defense, and judges in both Mercer and Coshocton Counties ruled it unconstitutional on First, Fifth, and Fourteenth Amendment grounds. Charges were dismissed against the parents, but as the Coshocton County Circuit Court Judge declared, “As of this date, a new standard of parental duty prevails in this jurisdiction.”

The rulings were not appealed because all sides got what they wanted, so they have effect only in those two counties. Mercer County Circuit Court Judge Dean James implored the legislature: “It is the hope of this Court that these types of cases will not have to be pursued by the prosecution in the remaining eighty-six counties.”

Contradictory laws ignored

We made many efforts during those seven years to move bills that repealed the criminal religious defense as well as the civil exemptions. We pointed out that Ohio had 86 counties where religious objectors had the legal right to let their children die without medical care and two where they did not. We thought that strange fact would surely get the legislators to see that they should correct the situation, but it did not. We had a petition with over a thousand signatures. We had newspaper editorials. The governor sent officials from two departments to testify for the bills. We had many respected organizations supporting our bills and only the Christian Science church opposed to it.

In 1989 the Ohio legislature did the bare minimum to get its federal money restored, repealing the religious exemption in the civil code but not the criminal code.

CHILD asks feds to review all exemptions

Trying to take advantage of HHS’s action against Ohio, Michael Botts (see above right), an attorney and CHILD member, prepared a 17-page analysis of state religious exemption laws showing that many had the same deficiencies that HHS had ruled Ohio out of compliance for. We sent this document to HHS.



HHS made a conscientious effort to improve the religious exemption laws it had imposed on the states. It undertook a years-long review of the laws and then wrote to the states about the problems it saw. Many states were able to satisfy compliance requirements by having their Attorneys General write opinions on the scope of their religious exemption laws. Some did enact helpful changes.

California sues

Others fought back. When HHS ruled California out of compliance, the state filed suit against HHS and complained that changing the religious exemption laws was “politically impossible.” CHILD filed an amicus brief arguing that the laws deprived children of fundamental rights.

Rituals better than medical care in Louisiana

The Louisiana legislature passed a resolution claiming that spiritual healing has been “safe and legal” in Louisiana for over one hundred years and that “the rate of serious illness and death” among those who rely on spiritual healing is “now averaging less than half that of the normal population.”

Congressmen sent long interrogatories for HHS to answer, rather obviously prepared by lawyers trying to construct a suit against HHS.

Congress ends HHS efforts

In 1994, after receiving a deluge of complaints from Christian Scientists, Congress intervened directly to pass a moratorium prohibiting HHS from requiring any changes in state laws pertaining to medical care. The battle over the moratorium took CHILD literally hundreds of hours.

In 1996, despite every ounce of opposition we and many other organizations could muster, the Republican-controlled Congress passed a law stating that there was no “federal requirement that a parent or legal guardian provide a child any medical service or treatment against the religious beliefs of the parent or legal guardian” and greatly weakened the federal definition of child abuse.

Church lobbied for religious defense to felonies

Since then, in our view, HHS has had little authority to require states to improve their child protection laws and has certainly not asked for any changes to religious exemptions. The Christian Science church got bills introduced modeled after the federal law. Bills offering a religious defense to felony crimes against children were introduced in Maryland, Wisconsin, Massachusetts, Oregon, and Delaware. Usually CHILD members were able to kill them. Oregon and Delaware did enact religious defenses to homicide, but we were later able to get them repealed.

After thirty years of our work only six states have absolutely no religious exemptions pertaining to medical care of sick or injured children. They are Hawaii, Oregon, Nebraska, Massachusetts, Maryland, and North Carolina. Oregon required several trips in 1998-99 to get five religious exemptions repealed and then the Swans' moving there in 2011 to get repeal of the other four exemptions, including religious defenses to homicide by abuse or neglect and manslaughter.

Total success in Massachusetts and Maryland

Massachusetts, the headquarters of the Christian Science church, took five years of hard work led by CHILD members Jetta Bernier and Ken Casanova.

In Maryland CHILD member Ellen Mugmon has gotten several exemptions repealed and has prevented the Christian Science church from getting exemptions in the criminal code.

Substantial improvement in other states

Beyond the six states whose laws we consider ideal many others have better laws through our work. South Dakota repealed five exemptions in 1990. Colorado repealed all its religious defenses to felonies in 2001.

Some have jiggered the wording so that it protects only a right to pray and not a right to withhold necessary medical care. Rhode Island had a religious defense to manslaughter when CHILD's medical consultant Dr. Seth Asser organized lobbying for repeal in 2004. The legislature balked at repeal, but we did get a compromise that makes Rhode Island's exemptions essentially meaningless. The criminal code exemption now says a person

relying exclusively on prayer "shall not, for that reason alone be considered an abusive or negligent parent or guardian; *provided the provisions of this section shall not (1) exempt a parent or guardian from having committed the offense of cruelty or neglect if the child is harmed. . . .*" (emphasis added) RI Gen. Laws 11-9-5(b)

Payments for Christian Science nursing upheld

CHILD has filed three lawsuits over the years. In one we got a ruling that Medicare/Medicaid payments for Christian Science nursing were unconstitutional, but Congress was very determined that these unlicensed nurses, who can't take a pulse or use a fever thermometer, should be reimbursed with public money and enacted new language to reimburse "religious non-medical health care institutions." We filed suit challenging those reimbursements also. The courts ruled against us, holding that the Christian Science nurses' "non-medical services" were a subset of medical care. We disagree in that these nurses do not work under supervision of state-licensed providers. They have no medical training, can't diagnose, and sometimes they do more harm than good with their menial services as when one force-fed a toddler with a bowel obstruction.

Eight amicus briefs

CHILD has had better fortunes with its amicus briefs. We've filed eight and have been on the winning side in six cases. Often a goodly number of national and state organizations sign on to our briefs. We are especially grateful to Professor Jim Dwyer at the William and Mary College of Law, who has written five amicus briefs for CHILD *pro bono*.

National organizations that have adopted positions against religious exemptions from child health laws have done so after input from CHILD members. These include the American Academy of Pediatrics, American Medical Association, Prevent Child Abuse America, National District Attorneys Association, and the National Association of Medical Examiners.

Pediatricians support CHILD's policy work

Our strongest ally has always been the American Academy of Pediatrics. They have often joined forces with us, sometimes on only a few hours

notice. In 1984 they retained a Washington DC law firm to help us defeat a U.S. Senate amendment on “the health care and treatment a parent may provide his child in the exercise of the parent’s freedom of religion.” The law firm quickly stirred up so much opposition that the church itself asked for the amendment to be withdrawn on the Senate floor. A decade later the AAP retained another DC law firm to write an amicus brief in support of one of our lawsuits.

Bills required payment for prayer

In 2010 we had a rare and important victory in Congress. As health-care reform went through, bills in both the House and Senate had provisions requiring that public and private insurers reimburse for Christian Science “treatment.” Such treatments consist only of prayer and church “practitioners” send bills for them. With help from the pediatricians, many members of secular humanist organizations, and others, we got those provisions dropped from the final bill.

Prayer treatment not essential health benefit

Since then the church has tried to get the U.S. Dept. of Health and Human Services to impose the reimbursements by regulation. It has also gone state-by-state attempting to get states to include their treatments and nursing care as an “essential health benefit” that insurers must reimburse. The church has not succeeded anywhere with those endeavors.

At this writing the church is lobbying for HR1814 and S.862 to exempt those with sincere religious beliefs against medical care from the mandate to purchase health insurance for themselves and their families. CHILD’s opposition to the bills is presented at the In Focus section of our webpage.

Two churches oppose corporal punishment

Although best known for our work on religion-based medical neglect of children, we’ve also worked on other forms of ideological child abuse and neglect. In 2004 we got the United Methodist Church to adopt a position discouraging corporal punishment by parents and calling for laws prohibiting it in schools and child-caring facilities. In 2012 The Presbyterian Church of America adopted a position closely modeled on it. We hope to get some other denominations to adopt similar

statements. They contradict the rhetoric of some fundamentalist leaders who claim corporal punishment is mandated by the Bible.



Support group meetings

For twenty years CHILD had annual meetings for ex-Christian Scientists to come together and share experiences and insights. The first meeting was in our home, where a member gave us “Banned in Boston” t-shirts. I wore mine to every meeting. Doug wore his until another member gave him a Bugs Bunny “animal magnetism” t-shirt. (“Malicious animal magnetism” is Mary Baker Eddy’s name for an unreal, but very terrifying force that tries to defeat Christian Science.) Several echoed the feelings of this participant in a book of letters we were given:

I never imagined people like you existed. It’s kind of like growing up gay and thinking you’re the only one and then you discover there ARE people out there who are like you and will help you by standing up against what has been wrong in your world. In my case it was child abuse (physical and sexual) as exacerbated by the isolation within the insane mumbo-jumbo which is Christian Science—a twisted ball of kindly-sounding platitudes. In the end, though, it boils down to the fact that if you get sick or something goes wrong, it’s your fault because you didn’t keep your mind clear or resist all medical intervention. If you die, that’s a source of shame as we are all meant to ascend to heaven just as Jesus did. And then I found you!

One of my favorite activities as CHILD’s president is helping students with papers on belief-

related abuse and neglect. They are the next generation, who will have to make our world a better place.

We've had a long relationship with one student and her family: Kathryn Skilton in Nashua, Iowa. She contacted us as a pony-tailed seventh grader



doing a paper on our work for a National History Day competition. She won at the state level and qualified for the national competition. Later she won a statewide writing contest with a paper about me for Women's History Month. Today she's a student at the University of Virginia School of Law.

CHILD members and officers have gotten belief-based abuse and neglect issues into the academic and professional community with presentations at conferences and publications. I've spoken at 40 conferences, including many national ones for child abuse professionals. The activities of our board and officers can be found in the About section of our webpage. Pediatrician Seth Asser and I published the largest study of child mortality in faith-healing sects, which has been widely cited. This *Pediatrics* article is available in the Resources section of the webpage.

I've been on national television 23 times and on regional TV programs many times also. Media coverage was indispensable to building CHILD in the early years. Being interviewed by Bill Moyers was especially meaningful to Doug and me. His twenty-minute report was excellent.

Church could not stop Donahue program

We're especially grateful to Phil Donahue, who gave complete unknowns who had never been on any TV program before, an hour on national television. Three church officials flew from Boston and met with Donahue and his producer to try to talk him out of doing the program but refused to face us on camera. The church nearly always refused to face us in front of a live studio audience.

Church got some TV programs cancelled

Many TV producers were less courageous than Donahue. They would invite me to appear and then disinvite me because the church refused to come on the show if I were there. *Larry King Live* did that more than once. *Good Morning, America* was another. Later *ABC World News Tonight* called and wanted info. I complained about my treatment by *GMA*, and the producer said, "The Christian Science church is an established international institution. Of course it's more important for us to get their view than yours." But she still wanted information from me and before the days of CHILD's copier, I had to drive 15 miles into town, get it copied, and express-mail it to her.

Nancy Reagan's astrologer takes precedence

I remember one time we were asked to fly to New York on very short notice. We almost literally threw the dog into the vet clinic on the way to the airport. Our travel agent (who is still a CHILD member) met us there with the tickets and we managed to get on the plane. But when we checked in at the NYC hotel, the program called and said they were canceling our appearance because of other "breaking news" they had to cover. We watched the next morning and the breaking news was that Nancy Reagan had consulted an astrologer.

There was also the producer who wanted to film an empty crib in our home, but we didn't have one, so we had to drive to a neighbor's home, borrow her crib, and set it up in our home.

Once when we were away from home, producers were so intent on finding us that they called the volunteer fire department in our little village. The number rang to twenty homes at once, none of whom knew where we were.

Most media don't stick with topic to conclusion

I have no complaints about those long-ago experiences. We did not spend a dime to solicit media coverage and we got plenty that helped hurting people find us and led to information about other cases. Still it is sobering to see how much the media misses. Only a handful of newspapers and TV programs have had the tenacity to stick with legislative work, and 177 minor children and stillbirths were buried in one cemetery used by the



Doug, Bill Moyers, Sharon Lutz, and Rita in front of Sharon's home (1984)

Idaho Followers of Christ before there was media coverage of the sect's rejection of medical care.

Some states still have religious defense to manslaughter

Looking back, I'm proud of what we've accomplished, but the progress in legislation has been painfully slow and an unbelievable amount of work. I had a dream of at least getting rid of all religious exemptions from manslaughter and negligent homicide charges but that's unlikely to happen in my lifetime. Five states have removed those particular exemptions since we began our work, but five or six states still have them, not in the manslaughter statutes themselves but because the prosecutor is required to prove a lesser crime that does have a religious defense in order to prove manslaughter.

We are grateful for the progress we've made toward getting children equal protection and building public awareness of religion-related child abuse and neglect. We maintain a special interest in public policy; we tend to highlight cases that illustrate deficiencies in public policy. We try to describe

how policies could be made more protective.

Above all we are grateful for the trust, kindness, and generosity of CHILD's members, many of whom have been with us for decades on this slow journey toward equal protection of the law for children.

About CHILD

A tax-exempt charity, CHILD works to stop child abuse and neglect related to religious beliefs, cultural traditions, or quackery. CHILD provides research, public education, and amicus briefs. It opposes religious exemptions from child health and safety laws as discriminating against children and does a limited amount of lobbying for equal protection of children.

CHILD membership dues are \$40 a year for an individual or family or \$15 a year for a full-time student.

A membership form, information about our work, and contact information for our board and officers is at www.childrenshealthcare.org.