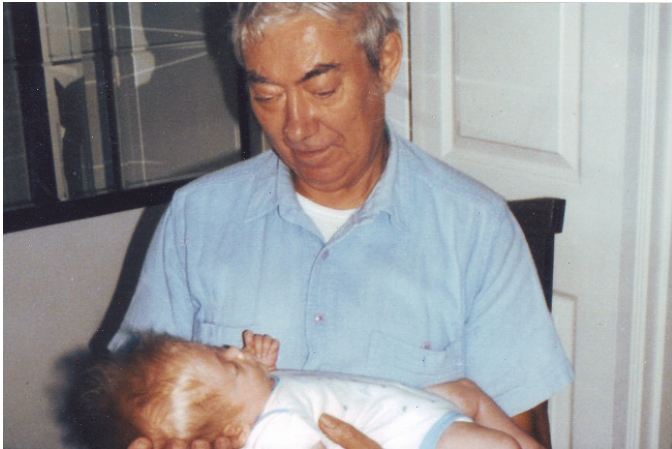


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*Anne Fuchs and her Grandfather*

## Chicken Little

*by Karl Fuchs*

Amy and I met as engineers for a telecommunications firm in early 1994. We started dating in the spring of that year, and by summer Amy was pregnant. Amy was and is a devout Christian Scientist. I knew very little of Christian Science when I met Amy. I never thought religion to be a very important factor to consider when dating someone. I would ask Amy about her religion, and at times I would tease her about her being a faith healer. Most of the things she told me about her religion went in one ear and out the other. I had very little interest in the seven synonyms for God, and I always thought Animal Magnetism meant women couldn't resist you.

When we discovered that Amy was pregnant, it was a great shock to both of us. In hindsight it shouldn't have been. I'd managed to meet the only woman on the East Coast who wasn't on birth control pills. Quite frankly, I wasn't ready to be a

father, but in October, 1994, Amy and I decided to get married and raise our new family.

Amy wanted to have natural childbirth attended by a midwife. She told me stories of terrible experiences other women had with hospital deliveries. I didn't have a problem with natural childbirth. I thought taking drugs during labor and delivery was a decision that should be up to the mother.

Amy, however, was getting no prenatal care. We did take Lamaze classes and searched for a birthing center, and Amy retained Christian Science practitioners to do "metaphysical work" for her and the baby.

Meanwhile, I began educating myself on Christian Science. I had Amy explain how all disease is an "error of thought," but I needed another point of view. I began reading books such as Richard Breneman's *Deadly Blessings* and others to get a more balanced picture. The more I read the more concerned I became.

With the Lamaze classes over, and a belly steadily growing, Amy decided on a birthing center and a midwife many miles away in Maryland. With only a few months left in the pregnancy, Amy finally got her first medical checkup. A blood test showed Amy to be very anemic. Furthermore, her blood was very low in vitamins and other minerals. I was also startled to learn at the checkup that Amy had never been vaccinated against any diseases.

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## Supplements refused

This marked the first time Amy and I had any real run-in over Christian Science. The midwives had prescribed vitamin and iron pills for Amy to take. She would have none of it. I told Amy that I desperately wanted her to take the pills, but she steadfastly refused.

Amy told me she was working on the problem with her Christian Science practitioner. That only alarmed me more. She might as well have told me she was going to bury a brown egg under the elm tree at midnight and chant.

A week or two later it was time for another checkup. A second blood test showed her iron levels to be even lower than the first. The baby was sucking iron out of her like a magnet. I thought, fine, clearly the Christian Science isn't working, and now she will take the iron pills.

## Failures don't impress Christian Scientists

That is when I discovered the greatest strength of Christian Scientists lies in their ability to rationalize away any failure of Christian Science. In essence, Amy thought by working harder, by truly believing, or by realigning herself with God, her body would acquire normal levels of nutrients. Also, Amy said she could not have prayer treatments from a Christian Science practitioner if she took pills.

The midwives had explained the importance of taking the iron and vitamins, but had also allowed Amy time to "heal" the problem with prayer. By the third blood test, however, they were ready to give us the boot. I was getting worn out with begging, pleading, and screaming for Amy to take some pills. In addition, the baby still had not turned. The birthing center would not handle a breech delivery. Amy and I were forced to seek an obstetrician.

Amy found a wonderful obstetrician associated with Arlington Hospital. We had only a few weeks before the baby was due. Amy started to go into labor but it didn't progress far. The doctor needed to do a caesarean section. Oddly enough, I don't remember Amy objecting to this decidedly medical procedure.

Despite my fear of surgery, I donned surgical scrubs and stood beside Amy in the operating room.

A few minutes and a bunch of blood later, Anne Thea Fuchs was born on April 7, 1995.

## Spina bifida

The doctor immediately told us she had spina bifida. I searched the limited medical lexicon of my mind for spina bifida and came up dry. But from the looks on the doctors' and nurses' faces, both Amy and I knew it wasn't good. They quickly rushed Anne into the neonatal ICU. I stayed while they "closed" Amy. It was about an hour before we began to understand how bad Anne's condition was.

## Chicken Little

After Amy was moved out of the operating room and into recovery, I was able to go to the neonatal ICU and see our baby daughter. This tiny creature, the extension of our hopes and dreams, I nicknamed Chicken Little. But I dissolved into a bawling mass of tears as I looked at her open, raw back and exposed spine. I couldn't really comprehend what the doctors were talking about. All I knew was they were transferring her to Children's Hospital in Washington DC. They brought Anne in to see Amy before they took her away.

The next day I spoke to Anne's primary doctor at Children's. She explained spina bifida and hydrocephalus over the phone. I knew Amy had to rest and recuperate after her surgery so I told her I had spoken to the doctor and that Anne was fine.

A few days later we went down to Children's Hospital. There we did a three-minute scrub and then went into the ward to see our baby. Anne was resting quietly, on her stomach with her back bandaged. We couldn't pick her up and hold her; we could only touch her head and hold her tiny hand.

## Catastrophic handicaps

Later, we met Anne's primary doctor, the head of spina bifida care at Children's Hospital. The meeting was awful. I was crying; Amy was crying. The doctor tried to be very kind and supportive, but there was no good news coming out of her.

Some sound bites stick with me to this day. The doctor said Anne had one of the most severe cases of spina bifida she had seen. She said Anne would be totally paralyzed for life. She would most

likely have learning disabilities and a lifetime of surgeries.

We had had all we could take for that day. We spent some more time with Anne and then we had to go home. I can't describe how full of sorrow Amy and I were. Amy immediately contacted her Christian Science practitioner and began "working" on Anne's case. I certainly had no problem with anyone praying for Anne; I know my friends and family were.

We went back to the hospital the next day to see Anne. We talked to more doctors and eventually social workers. Neurosurgeons described putting in shunts to drain fluid from Anne's brain. Other specialists told us they would close her back. No one in this parade of doctors gave us any hope that the medical community could do anything for Anne other than patch her up. No one could make her better. No one could give Anne any quality of life at all.

### **Baby brought home; hospice care provided**

Amy and I listened to everything the doctors had to say. I felt Anne's case was beyond the capability of modern medicine. Amy was sure she had a much better health system to rely on. Then, unexpectedly, Amy and I came to the exact same decision from two very different perspectives. With the approval of the doctors at Children's Hospital, we took Anne home with nothing more than a bandage on her back.

Discharging Anne from the hospital came with one condition: we had to put her in hospice care. Hospice workers give comfort and aid to terminally ill patients. Their main objective with Anne was to monitor her condition and ensure she was not in any pain. Thank God she never was.

### **Religion of denial**

Amy really didn't want to have much to do with hospice. Naturally, she was very concerned and a very wonderful, attentive mother. Given her religion of denial, however, I had the weekly conversations with the hospice workers. Once a nurse told me Anne was blind. Other workers told me how Anne's hydrocephalus was contorting her head. All the while, Amy and her Christian Science

practitioners would pray. Clearly, there is no harm in that.

Eventually, Anne's condition worsened. One Friday morning in November, 1995, Anne passed away.

I won't try to describe the pain and grief we and our relatives felt. Amy and I just tried to do the best we could to "pick up the pieces" and move on. The whole ordeal was an enormous strain on our marriage. During the months and years that followed, we worked very hard to rebuild and strengthen our relationship. We took SCUBA lessons together. We went on numerous vacations together, just to reconnect.

### **Excuses for failure**

What amazed and disappointed me more than anything else was that, even after Anne's death, Amy never once wavered from her belief in Christian Science. She would use all the standard Christian Science rationalizations, e.g. her faith wasn't strong enough, Anne was born sick because premarital sex had put Amy "out of grace" with God. Amy even tried "Anne died because you thought death was best for her."

I thought for sure, after Christian Science had let Amy down when she needed it most, she would think, "Hey, maybe this stuff doesn't work after all." I had hoped if anything good could come from that awful experience, it would be that Amy might open herself to rational thought. That did not happen.

### **Another baby by Christian Science rules?**

A few years later Christian Science dropped another bombshell in my life when Amy announced she wanted to have another child. She was now over 40 years old. I tried to persuade her to get prenatal care, but, as I expected, she refused.

Amy then filed for divorce. I know she was very angry at me for "keeping her barren," but I know deep in my heart I did her and some unconceived child a huge favor. I only wish I could have done something to help my only child, Chicken Little, before or during her brief life with us.

## Folic acid reduces birth defects

Baby Anne's heart-rending case above is not the only one we know of in which a severely handicapped child has been born to a Christian Science mother who refused to take vitamins and iron.

While the causes in individual cases cannot be known for certain, medical science has well established that folic acid (a B vitamin) and iron prevent some birth defects and other problems for babies.

### NTDs can be prevented

The National Council on Folic Acid states that folic acid is necessary for proper cell growth and can prevent from 50 to 70% of the birth defects called neural tube defects (NTDs).

NTDs include spina bifida, the leading cause of childhood paralysis, and anencephaly, which is always fatal. They affect an estimated 4,000 U.S. pregnancies each year.

New research suggests that folic acid can also help prevent other birth defects, such as cleft lip and cleft palate.

### Supplements should be taken before pregnancy

In 1992 the U.S. Public Health Service recommended that all women of childbearing years should take 0.4 mg of folic acid daily. The fetus's neural tube is formed very early in the pregnancy, so women should be taking the folic acid even before they become pregnant to be sure of getting its preventive benefits.

It is difficult to obtain the recommended dosage from foods. The body actually absorbs the synthetic form of folic acid better than the natural form.

Source: [www.folicacidinfo.org](http://www.folicacidinfo.org).

## Obstetrics, Christian Science style

The pregnant Christian Scientist's peculiar mix of compliant and defiant behavior as described in Karl Fuchs's article above is a product of her church's shifting legal strategies.

In the early days of Christian Science, founder Mary Baker Eddy advertised her instruction in

"metaphysical obstetrics," and her students reported many cases of attending childbirth successfully by using her teaching.

In 1888, however, one of her students, Abby Corner, was indicted for manslaughter after she tried to attend a delivery in which both mother and baby died.

### Eddy denounces student in press

Fellow students wanted to come to Corner's defense and support her publicly, but Eddy denounced her in the *Boston Herald* as a quack who had not taken Eddy's new course in metaphysical obstetrics. The course consisted of six lectures, five on demonology and one on how to deny "false claims" associated with childbirth such as prematurity, breech presentation, and labor pains. As Willa Cather commented in *The Life of Mary Baker Eddy*, the lecture denied everything about childbirth except the baby. The tuition was \$100 in 1887.

After the public relations fiasco of the Corner case, Eddy initiated an intense, sudden friendship with a homeopathic physician, Dr. Ebenezer Foster, and asked him to be her legally adopted son. In her 1888 course on metaphysical obstetrics, she had him teach "the anatomy and surgery of obstetrics" while she taught the metaphysics. Then she closed her college.

### Misleading presentation of state laws

Today the church says Dr. Foster's participation shows that Eddy wanted church members to retain a medical doctor to provide the "technical assistance" needed at childbirth. A concordance to Eddy's published writings does not disclose such advice.

The modern church also tells members that state laws require them to retain a state-licensed physician or midwife for childbirth. In fact, however, there are no such state laws. The church's claims about the laws seem to be intended to deflect attention from Eddy's inconsistencies. It is, in any case, bizarre for the church to claim that non-existent laws require medical attention at childbirth, but not to tell members about actual laws requiring medical attention for sick and injured children.

Most Christian Scientists engage a medical doctor for childbirth, but many follow church theology in refusing iron, vitamin supplements, and drugs for themselves as well as prophylactic measures and testing for their newborns.

### **Some doctors accommodated CS beliefs**

Through much of the twentieth century Christian Scientists and their church often found various ways of getting doctors to accommodate their beliefs. Church members shared their experiences with practitioners, who then told expectant mothers which doctors did things the way Christian Scientists wanted. Some doctors would deliver babies in the parents' homes. Some doctors allowed Christian Science "nurses" to assist them in lieu of registered medical nurses.

Los Angeles even had the Griffith Park Maternity Home specifically for Christian Scientists, where some medical doctors came and delivered babies while the church's unlicensed nurses provided other care.

### **OB claims CS miracles anonymously**

A favorite was Dr. John Hale, an obstetrician in the Woodland Hills-Canoga Park area, who attended more than 250 Christian Science births. His letter was published in Robert Peel's *Spiritual Healing in a Scientific Age*, a book consisting largely of testimonies gathered by the church after CHILD founders Rita and Doug Swan appeared on *Donahue*.

Hale's unsigned letter claimed he had seen "many demonstrations through faith in the principles discovered by Mrs. Eddy." He described in detail one woman whose labor did not progress because the baby's shoulder was presenting first. He made arrangements for a caesarean section, but within fifteen minutes the baby had turned so that a vaginal delivery could take place. Hale called this a medical impossibility and "irrefutable" proof that Christian Science heals.

### **No miracles claimed in signed letter**

In 1989 Hale submitted signed written testimony to the California legislature in support of a bill giving Christian Scientists a *carte blanche*

religious exemption from prosecution for felony crimes against children. Some sections were verbatim from the unsigned letter in Peel's book. Significantly, however, Hale did not describe any Christian Science healings over his own signature.

### **Nurses lock mom and baby in building alone**

Not everyone was pleased with the care in Griffith Park Maternity Home. One woman wrote CHILD that after she delivered her baby there, the Christian Science nurses locked the building and left for the night. She and her baby were the only people in it.

A doctor in Boston complained to CHILD members that the Christian Science nurses who joined him for delivery of babies refused even to hold his sterile instruments.

### **Nurses won't do anything "material" to heal disease or relieve pain**

Indeed, it is hard to imagine how Christian Science nurses could ever be satisfactory assistants to medical doctors. They have no training in first aid. They cannot take a pulse or use a fever thermometer. Touching the body to relieve discomfort is against their religion. Suzanne Shepard describes in a *Redbook* article her mother-in-law choking in a Christian Science nursing home; the nurses would not help her and even ordered Suzanne out of the room for helping her mother-in-law to sit up and catch her breath. Christian Science nurses will not apply heat or ice to an inflamed area or give back-rubs. Christian Science founder Mary Baker Eddy plainly says that a person cannot apply "a single material application" for the "relief" of suffering if he wants help from Christian Science.

Griffith Park Maternity Home has closed; Dr. Hale is no longer in practice. Nearly all obstetricians today want to deliver babies in hospitals or birthing centers where they have access to the equipment and trained personnel they may need. And with the discovery that folic acid prevents spina bifida and other catastrophic birth defects, most doctors would surely insist that patients who are or may become pregnant take folic acid and iron supplements.

Sources include Robert Peel's *Spiritual Healing in a Scientific Age*: 116-19; M.B. Eddy's *Science and Health with Key to the Scriptures*: 421; Willa Cather and Georgine Milmine, *The Life of Mary Baker Eddy and the History of Christian Science*: 354-56; Edwin Dakin, *Mrs. Eddy: the Biography of a Virginal Mind*: 239-42; Suzanne Shepard, "Suffer the little children," *Redbook*, October 1994:68-72; and church-produced booklets entitled *Legal Rights and Obligations of Christian Scientists in [various states]*.

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## Nebraska's new screening regulations

In 2002 Nebraska adopted regulations for metabolic screening of newborns that, in CHILD's view, are the best in the nation. No religious or philosophical exemptions are allowed. A physician attending a birth must cause a blood specimen to be collected for the testing when the infant is between 24 and 48 hours old. If the infant is discharged from the hospital before 24 hours after birth or has symptoms indicating the test should be done immediately, it can be done earlier, but then will have to be done a second time during the infant's first week of life.

### Test required for birth certificate

For births not attended by a physician, the person registering the birth must cause newborn screening tests for metabolic disease to be done within 48 hours of registering the birth.

The regulations have an enforcement mechanism allowing a district attorney to bring a civil proceeding against a parent to have the metabolic screening done.

Metabolic screening involves taking a few drops of blood from a baby's heel. The blood is then tested for metabolic diseases such as phenylketonuria (PKU), galactosemia, hypothyroidism, medium-chain acyl-CoA dehydrogenase deficiency, hemoglobinopathies, maple syrup urine disease, and others.

The new technology of tandem mass spectrometry makes it possible to test for more than 30 diseases by analysis of one spot of blood.

Many of the metabolic disorders are readily treatable. Simple dietary control for a few years prevents damage from PKU, for example.

Without treatment, severe consequences result, including mental retardation, growth retardation, failure to thrive, liver disease, oxygen-carrying difficulties, and sudden infant death.



*A nurse takes a blood sample from a newborn*

### Timing crucial

Timing of the test and of getting results back to a physician is extremely important. The test may not accurately detect PKU if blood is taken before the infant is 24 hours old, yet infants can die within days if galactosemia is not treated.

At [www.savebabies.org](http://www.savebabies.org), many families have accounts of their ordeals with metabolic diseases that were not detected promptly. In 1998, a Georgia mom and baby Tyler were discharged from the hospital before he was 24 hours old, as is all too common practice today. Since the test could not accurately detect PKU from blood taken at his age, a nurse encouraged the family to wait and have the test done at their pediatrician's office. It was done when he was five days old.

Tyler became violently ill and died at nine days old. Five days after his death, the test results came back showing that he had galactosemia.

CHILD wrote to Nebraska Health and Human Services in support of the draft regulations during

the public comment period. We believe metabolic testing for some diseases should be required without exception for parents' attitudes. And we have long felt that requiring evidence of metabolic testing on birth certificates is a simple, non-punitive, and non-obtrusive way of getting testing for babies whose births are not attended by physicians.

Nebraska's excellent regulations are under challenge by the Church of Scientology (see p. 7).

## The brave new world of testing: ethical considerations

The cover of *Discover* magazine's July, 2003, issue proclaims: "Now the genetic testing really begins. It starts with a single drop of blood taken from each newborn and ends when scientists predict everyone's physical and mental future."

The mapping of the sequence of human DNA through the Human Genome Project makes it possible to test persons for innumerable genes. "Conceivably, we could do 50,000 genetic tests using DNA chips right at the bedside," says University of Utah pediatrics professor Jeffrey Botkin.

Furthermore, scientists are coming to realize that "virtually every disease has a genetic component," says Wayne Grody, a UCLA professor of medical genetics.

These developments coupled with the rapid advance of testing technology raise ethical questions. Should babies be tested for genes that might cause diseases forty years from now? Should they be tested for genes influencing personality types or emotional states? Should insurance companies and employers have access to testing results?

**CHILD's position is that screening of newborns should be required only when it meets the following conditions:**

1. The disease has significant mortality and morbidity among children when not diagnosed presymptomatically
2. The disease is not consistently identified clinically in the neonatal period
3. The prevalence of the disease in the child population is significant

4. The baby can benefit from pre-symptomatic treatment
5. The screening method is simple, minimally invasive, and carries no reasonable risk of physical harm
6. The screening method is sensitive and specific
7. A reliable means for reporting results exists
8. The purpose of the screening is explained to the parents, and resources for treatment and counseling are available.
9. A baby's test results will be disclosed only to parents and the baby's physician.

These conditions are similar to those set forth by the Joint Report of the Association of Public Health Laboratories and Council of Regional Genetic Networks.

### Standard: potential benefit to child

No test should be required for purposes of research. No test should be required if medical science does not have an effective treatment for the disease. The standard should be the potential personal benefit to a child.

What constitutes "significant" prevalence of disease in the child population will be debated and decided by policymakers. Phenylketonuria affects about one infant in 16,000, galactosemia about one in 53,000, and maple syrup urine disorder, which some states test for, about one in 183,000. Putting together all the metabolic and genetic disorders detectable by present technology, the odds of finding one in any given infant are one in 2,000.

The metabolic disorders are not common. But they cause devastating injury and death if not detected by a test and treated. The test is very simple, and so is treatment. Those factors weigh heavily in favor of requiring screening for some metabolic disorders.

Sources include Association of Public Health Laboratories, "Recommendations and Standardization of Neonatal Screening" (Washington, D.C.: March, 1999):15 and Jeff Wheelwright, "Testing your future," *Discover* 24 (July, 2003):35-41.

## Scientology seeks religious exemption in Nebraska

Members of the Church of Scientology have gotten a bill, LB714, introduced in Nebraska to allow a religious exemption from metabolic screening of newborns. It was tabled, but will probably be brought up again next year.

Scientologists Ray and Louise Spiering of Wahoo, Nebraska, testified before the Unicameral's Health and Human Services Committee explaining their church's belief in "Silent Birth," which prohibits speaking any words to the newborn or inflicting



*Scientology Headquarters in Los Angeles*

any pain before the infant is a week old. The church therefore opposes drawing the few drops of blood needed for metabolic testing during that period.

### **"Silent Birth" needed to protect mental health**

Ray Spiering testified that the brain has a primitive part called the reactive mind that is "survival-oriented" and cannot reason. Pain activates the reactive mind to record the details of the current situation, such as smells and sounds "and especially words themselves," he said.

Later, when an individual encounters the same sensory data or words, his primitive mind turns on its old recording and tells him to fight or flee and can make him relive the pain of an earlier experience, Spiering said. He also described how Scientology's "dianetics" helped a person troubled by replays of early trauma.

Because a newborn has been through so much pain during the birth process, Scientology believes she should not be subjected to any pain or hear any words until she is several days old.

The committee amended the bill, changing it from a *carte blanche* religious exemption to the following:

"A parent or guardian acting on the basis of sincerely held religious beliefs may delay the specimen collection past the period prescribed by the department. Such parent or guardian shall sign a waiver prescribed by the department and shall ensure that the specimen is collected no later than ninety-six hours from the time of birth at a birthing facility or laboratory otherwise competent to collect the specimen."

### **No scientific evidence**

The Church of Scientology is well known for its vicious attacks on psychiatry and for promotion of its expensive galvanometers, e-meters, and dianetics as appropriate treatment for mental health problems. In Nebraska it is asking for a religious exemption on the basis of unscientific theories about the brain.

Several psychiatrists and psychologists we contacted said they know of no scientific evidence to suggest that birth trauma or having a few drops of blood drawn has any after-effects on mental health.

One pointed out that babies can hear words for many weeks before they are born. Others pointed out that scientific research indicates that talking to newborns is therapeutic. It enhances bonding.

Science has also established that metabolic testing should be done before the baby is 96 hours old. According to R.D Adams in *Principles of Neurology*, 6<sup>th</sup> ed.:931, "The importance of these [metabolic] diseases relates not to their frequency (they constitute only a small fraction of diseases that compromise nervous system function in the neonate) but to the fact that they must be recognized promptly if the infant is to be prevented from dying or from suffering a worse fate, that of a lifelong severe mental deficiency. This inherent threat introduces an element of urgency into neonatal neurology."



At [www.savebabies.org](http://www.savebabies.org) many families have accounts of their ordeals with metabolic diseases that were not detected promptly.

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### **About CHILD Inc.**

CHILD is a national membership organization dedicated to preventing child abuse and neglect related to religion or cultural traditions.

See [www.childrenshealthcare.org](http://www.childrenshealthcare.org) for more information and a membership application form. To reach CHILD by mail, phone, fax, or e-mail, see the contact information on page 1.