1

Birth

If Lia Lee had been born in the highlands of northwest Laos, where her parents and twelve of her brothers and sisters were born, her mother would have squatted on the floor of the house that her father had built from ax-hewn planks thatched with bamboo and grass. The floor was dirt, but it was clean. Her mother, Foua, sprinkled it regularly with water to keep the dust down and swept it every morning and evening with a broom she had made of grass and bark. She used a bamboo dustpan, which she had also made herself, to collect the feces of the children who were too young to defecate outside, and emptied its contents in the forest. Even if Foua had been a less fastidious housekeeper, her newborn babies wouldn't have gotten dirty, since she never let them actually touch the floor. She remains proud to this day that she delivered each of them into her own hands, reaching between her legs to ease out the head and then letting the rest of the body slip out onto her bent forearms. No birth attendant was present, though if her throat became dry during labor, her husband, Nao Kao, was permitted to bring her a cup of hot water, as long as he averted his eyes from her body. Because Foua believed that moaning or screaming would thwart the birth, she labored in silence, with the exception of an occasional prayer to her ancestors. She was so quiet that although most of her babies were born at night, her older

children slept undisturbed on a communal bamboo pallet a few feet away, and woke only when they heard the cry of their new brother or sister. After each birth, Nao Kao cut the umbilical cord with heated scissors and tied it with string. Then Foua washed the baby with water she had carried from the stream, usually in the early phases of labor, in a wooden and bamboo pack-barrel strapped to her back.

Foua conceived, carried, and bore all her children with ease, but had there been any problems, she would have had recourse to a variety of remedies that were commonly used by the Hmong, the hilltribe to which her family belonged. If a Hmong couple failed to produce children, they could call in a *txiv neeb*, a shaman who was believed to have the ability to enter a trance, summon a posse of helpful familiars, ride a winged horse over the twelve mountains between the earth and the sky, cross an ocean inhabited by dragons, and (starting with bribes of food and money and, if necessary, working up to a necromantic sword) negotiate for his patients' health with the spirits who lived in the realm of the unseen. A *txiv neeb* might be able to cure infertility by asking the couple to sacrifice a dog, a cat, a chicken, or a sheep. After the animal's throat was cut, the *txiv neeb* would string a rope bridge from the doorpost to the marriage bed, over which the soul of the couple's future baby, which had been detained by a malevolent spirit called a *dab*, could now freely travel to earth. One could also take certain precautions to avoid becoming infertile in the first place. For example, no Hmong woman of childbearing age would ever think of setting foot inside a cave, because a particularly unpleasant kind of *dab* sometimes lived there who liked to eat flesh and drink blood and could make his victim sterile by having sexual intercourse with her.

Once a Hmong woman became pregnant, she could ensure the health of her child by paying close attention to her food cravings. If she craved ginger and failed to eat it, her child would be born with an extra finger or toe. If she craved chicken flesh and did not eat it, her child would have a blemish near its ear. If she craved eggs and did not eat them, her child would have a lumpy head. When a Hmong woman felt the first pangs of labor, she would hurry home from the rice or opium fields, where she had continued to work throughout her pregnancy. It was important to reach her own house, or at least the house of one of her husband's cousins, because if she gave birth anywhere else a *dab* might injure her. A long or arduous labor could be

eased by drinking the water in which a key had been boiled, in order to unlock the birth canal; by having her family array bowls of sacred water around the room and chant prayers over them; or, if the difficulty stemmed from having treated an elder member of the family with insufficient respect, by washing the offended relative's fingertips and apologizing like crazy until the relative finally said, "I forgive you."

Soon after the birth, while the mother and baby were still lying together next to the fire pit, the father dug a hole at least two feet deep in the dirt floor and buried the placenta. If it was a girl, her placenta was buried under her parents' bed; if it was a boy, his placenta was buried in a place of greater honor, near the base of the house's central wooden pillar, in which a male spirit, a domestic guardian who held up the roof of the house and watched over its residents, made his home. The placenta was always buried with the smooth side, the side that had faced the fetus inside the womb, turned upward, since if it was upside down, the baby might vomit after nursing. If the baby's face erupted in spots, that meant the placenta was being attacked by ants underground, and boiling water was poured into the burial hole as an insecticide. In the Hmong language, the word for placenta means "jacket." It is considered one's first and finest garment. When a Hmong dies, his or her soul must travel back from place to place, retracing the path of its life geography, until it reaches the burial place of its placental jacket, and puts it on. Only after the soul is properly dressed in the clothing in which it was born can it continue its dangerous journey, past murderous *dabs* and giant poisonous caterpillars, around man-eating rocks and impassable oceans, to the place beyond the sky where it is reunited with its ancestors and from which it will someday be sent to be reborn as the soul of a new baby. If the soul cannot find its jacket, it is condemned to an eternity of wandering, naked and alone.

Because the Lees are among the 150,000 Hmong who have fled Laos since their country fell to communist forces in 1975, they do not know if their house is still standing, or if the five male and seven female placentas that Nao Kao buried under the dirt floor are still there. They believe that half of the placentas have already been put to their final use, since four of their sons and two of their daughters died of various causes before the Lees came to the United States. The

Lees believe that someday the souls of most of the rest of their family will have a long way to travel, since they will have to retrace their steps from Merced, California, where the family has spent fifteen of its seventeen years in this country; to Portland, Oregon, where they lived before Merced; to Honolulu, Hawaii, where their airplane from Thailand first landed; to two Thai refugee camps; and finally back to their home village in Laos.

The Lees' thirteenth child, Mai, was born in a refugee camp in Thailand. Her placenta was buried under their hut. Their fourteenth child, Lia, was born in the Merced Community Medical Center, a modern public hospital that serves an agricultural county in California's Central Valley, where many Hmong refugees have resettled. Lia's placenta was incinerated. Some Hmong women have asked the doctors at MCMC, as the hospital is commonly called, if they could take their babies' placentas home. Several of the doctors have acquiesced, packing the placentas in plastic bags or take-out containers from the hospital cafeteria; most have refused, in some cases because they have assumed that the women planned to eat the placentas, and have found that idea disgusting, and in some cases because they have feared the possible spread of hepatitis B, which is carried by at least fifteen percent of the Hmong refugees in the United States. Foua never thought to ask, since she speaks no English, and when she delivered Lia, no one present spoke Hmong. In any case, the Lees' apartment had a wooden floor covered with wall-to-wall carpeting, so burying the placenta would have been a difficult proposition.

When Lia was born, at 7:09 p.m. on July 19, 1982, Foua was lying on her back on a steel table, her body covered with sterile drapes, her genital area painted with a brown Betadine solution, with a high-wattage lamp trained on her perineum. There were no family members in the room. Gary Thueson, a family practice resident who did the delivery, noted in the chart that in order to speed the labor, he had artificially ruptured Foua's amniotic sac by poking it with a foot-long plastic "amni-hook"; that no anesthesia was used; that no episiotomy, an incision to enlarge the vaginal opening, was necessary; and that after the birth, Foua received a standard intravenous dose of Pitocin to constrict her uterus. Dr. Thueson also noted that Lia was a "healthy infant" whose weight, 8 pounds 7 ounces, and condition were "appropriate for gestational age" (an estimate he based on observation

alone, since Foua had received no prenatal care, was not certain how long she had been pregnant, and could not have told Dr. Thueson even if she had known). Foua thinks that Lia was her largest baby, although she isn't sure, since none of her thirteen elder children were weighed at birth. Lia's Apgar scores, an assessment of a newborn infant's heart rate, respiration, muscle tone, color, and reflexes, were good: one minute after her birth she scored 7 on a scale of 10, and four minutes later she scored 9. When she was six minutes old, her color was described as "pink" and her activity as "crying." Lia was shown briefly to her mother. Then she was placed in a steel and Plexiglas warmer, where a nurse fastened a plastic identification band around her wrist and recorded her footprints by inking the soles of her feet with a stamp pad and pressing them against a Newborn Identification form. After that, Lia was removed to the central nursery, where she received an injection of Vitamin K in one of her thighs to prevent hemorrhagic disease; was treated with two drops of silver nitrate solution in each eye, to prevent an infection from gonococcal bacteria; and was bathed with Safeguard soap.

Foua's own date of birth was recorded on Lia's Delivery Room Record as October 6, 1944. In fact, she has no idea when she was born, and on various other occasions during the next several years she would inform MCMC personnel, through English-speaking relatives such as the nephew's wife who had helped her check into the hospital for Lia's delivery, that her date of birth was October 6, 1942, or, more frequently, October 6, 1926. Not a single admitting clerk ever appears to have questioned the latter date, though it would imply that Foua gave birth to Lia at the age of 55. Foua is quite sure, however, that October is correct, since she was told by her parents that she was born during the season in which the opium fields are weeded for the second time and the harvested rice stalks are stacked. She invented the precise day of the month, like the year, in order to satisfy the many Americans who have evinced an abhorrence of unfilled blanks on the innumerable forms the Lees have encountered since their admission to the United States in 1980. Most Hmong refugees are familiar with this American trait and have accommodated it in the same way. Nao Kao Lee has a first cousin who told the immigration officials that all nine of his children were born on July 15, in nine consecutive years, and this information was duly recorded on their resident alien documents.

When Lia Lee was released from MCMC, at the age of three days, her mother was asked to sign a piece of paper that read:

> I CERTIFY that during the discharge procedure I received my baby, examined it and determined that it was mine. I checked the Ident-A-Band® parts sealed on the baby and on me and found that they were identically numbered 5043 and contained correct identifying information.

Since Foua cannot read and has never learned to recognize Arabic numerals, it is unlikely that she followed these instructions. However, she had been asked for her signature so often in the United States that she had mastered the capital forms of the seven different letters contained in her name, Foua Yang. (The Yangs and the Lees are among the largest of the Hmong clans; the other major ones are the Chas, the Chengs, the Hangs, the Hers, the Kues, the Los, the Mouas, the Thaos, the Vues, the Xiongs, and the Vangs. In Laos, the clan name came first, but most Hmong refugees in the United States use it as a surname. Children belong to their father's clan; women traditionally retain their clan name after marriage. Marrying a member of one's own clan is strictly taboo.) Foua's signature is no less legible than the signatures of most of MCMC's resident physicians-in-training, which, particularly if they are written toward the end of a twenty-four-hour shift, tend to resemble EEGs. However, it has the unique distinction of looking different each time it appears on a hospital document. On this occasion, FOUAYANG was written as a single word. One A is canted to the left and one to the right, the Y looks like an X, and the legs of the N undulate gracefully, like a child's drawing of a wave.

It is a credit to Foua's general equanimity, as well as her characteristic desire not to think ill of anyone, that although she found Lia's birth a peculiar experience, she has few criticisms of the way the hospital handled it. Her doubts about MCMC in particular, and American medicine in general, would not begin to gather force until Lia had visited the hospital many times. On this occasion, she thought the doctor was gentle and kind, she was impressed that so many people were there to help her, and although she felt that the nurses who bathed Lia with Safeguard did not get her quite as clean as she had gotten her newborns with Laotian stream water, her only major complaint concerned the hospital food. She was surprised to be offered

ice water after the birth, since many Hmong believe that cold foods during the postpartum period make the blood congeal in the womb instead of cleansing it by flowing freely, and that a woman who does not observe the taboo against them will develop itchy skin or diarrhea in her old age. Foua did accept several cups of what she remembers as hot black water. This was probably either tea or beef broth; Foua is sure it wasn't coffee, which she had seen before and would have recognized. The black water was the only MCMC-provided food that passed her lips during her stay in the maternity ward. Each day, Nao Kao cooked and brought her the diet that is strictly prescribed for Hmong women during the thirty days following childbirth: steamed rice, and chicken boiled in water with five special postpartum herbs (which the Lees had grown for this purpose on the edge of the parking lot behind their apartment building). This diet was familiar to the doctors on the Labor and Delivery floor at MCMC, whose assessments of it were fairly accurate gauges of their general opinion of the Hmong. One obstetrician, Raquel Arias, recalled, "The Hmong men carried these nice little silver cans to the hospital that always had some kind of chicken soup in them and always smelled great." Another obstetrician, Robert Small, said, "They always brought some horrible stinking concoction that smelled like the chicken had been dead for a week." Foua never shared her meals with anyone, because there is a postpartum taboo against spilling grains of rice accidentally into the chicken pot. If that occurs, the newborn is likely to break out across the nose and cheeks with little white pimples whose name in the Hmong language is the same as the word for "rice."

Some Hmong parents in Merced have given their children American names. In addition to many standard ones, these have included Kennedy, Nixon, Pajama, Guitar, Main (after Merced's Main Street), and, until a nurse counseled otherwise, Baby Boy, which one mother, seeing it written on her son's hospital papers, assumed was the name the doctor had already chosen for him. The Lees chose to give their daughter a Hmong name, Lia. Her name was officially conferred in a ceremony called a *hu plig*, or soul-calling, which in Laos always took place on the third day after birth. Until this ceremony was performed, a baby was not considered to be fully a member of the human race, and if it died during its first three days it was not accorded the customary funerary rites. (This may have been a cultural adaptation to

the fifty-percent infant mortality rate, a way of steeling Hmong mothers against the frequent loss of their babies during or shortly after childbirth by encouraging them to postpone their attachment.) In the United States, the naming is usually celebrated at a later time, since on its third day a baby may still be hospitalized, especially if the birth was complicated. It took the Lee family about a month to save enough money from their welfare checks, and from gifts from their relatives' welfare checks, to finance a soul-calling party for Lia.

Although the Hmong believe that illness can be caused by a variety of sources—including eating the wrong food, drinking contaminated water, being affected by a change in the weather, failing to ejaculate completely during sexual intercourse, neglecting to make offerings to one's ancestors, being punished for one's ancestors' transgressions, being cursed, being hit by a whirlwind, having a stone implanted in one's body by an evil spirit master, having one's blood sucked by a *dab*, bumping into a *dab* who lives in a tree or a stream, digging a well in a *dab*'s living place, catching sight of a dwarf female *dab* who eats earthworms, having a *dab* sit on one's chest while one is sleeping, doing one's laundry in a lake inhabited by a dragon, pointing one's finger at the full moon, touching a newborn mouse, killing a large snake, urinating on a rock that looks like a tiger, urinating on or kicking a benevolent house spirit, or having bird droppings fall on one's head—by far the most common cause of illness is soul loss. Although the Hmong do not agree on just how many souls people have (estimates range from one to thirty-two; the Lees believe there is only one), there is a general consensus that whatever the number, it is the life-soul, whose presence is necessary for health and happiness, that tends to get lost. A life-soul can become separated from its body through anger, grief, fear, curiosity, or wanderlust. The life-souls of newborn babies are especially prone to disappearance, since they are so small, so vulnerable, and so precariously poised between the realm of the unseen, from which they have just traveled, and the realm of the living. Babies' souls may wander away, drawn by bright colors, sweet sounds, or fragrant smells; they may leave if a baby is sad, lonely, or insufficiently loved by its parents; they may be frightened away by a sudden loud noise; or they may be stolen by a *dab*. Some Hmong are careful never to say aloud that a baby is pretty, lest a *dab* be listening. Hmong babies are often dressed in intricately embroidered

hats (Foua made several for Lia) which, when seen from a heavenly perspective, might fool a predatory *dab* into thinking the child was a flower. They spend much of their time swaddled against their mothers' backs in cloth carriers called *nyias* (Foua made Lia several of these too) that have been embroidered with soul-retaining motifs, such as the pigpen, which symbolizes enclosure. They may wear silver necklaces fastened with soul-shackling locks. When babies or small children go on an outing, their parents may call loudly to their souls before the family returns home, to make sure that none remain behind. Hmong families in Merced can sometimes be heard doing this when they leave local parks after a picnic. None of these ploys can work, however, unless the soul-calling ritual has already been properly observed.

Lia's *hu plig* took place in the living room of her family's apartment. There were so many guests, all of them Hmong and most of them members of the Lee and Yang clans, that it was nearly impossible to turn around. Foua and Nao Kao were proud that so many people had come to celebrate their good fortune in being favored with such a healthy and beautiful daughter. That morning Nao Kao had sacrificed a pig in order to invite the soul of one of Lia's ancestors, which was probably hungry and would appreciate an offering of food, to be reborn in her body. After the guests arrived, an elder of the Yang clan stood at the apartment's open front door, facing East 12th Street, with two live chickens in a bag on the floor next to him, and chanted a greeting to Lia's soul. The two chickens were then killed, plucked, eviscerated, partially boiled, retrieved from the cooking pot, and examined to see if their skulls were translucent and their tongues curled upward, both signs that Lia's new soul was pleased to take up residence in her body and that her name was a good one. (If the signs had been inauspicious, the soul-caller would have recommended that another name be chosen.) After the reading of the auguries, the chickens were put back in the cooking pot. The guests would later eat them and the pig for dinner. Before the meal, the soul-caller brushed Lia's hands with a bundle of short white strings and said, "I am sweeping away the ways of sickness." Then Lia's parents and all of the elders present in the room each tied a string around one of Lia's wrists in order to bind her soul securely to her body. Foua and Nao Kao promised to love her; the elders blessed her and prayed that she would have a long life and that she would never become sick.

2

Fish Soup

In an intermediate French class at Merced College a few years ago, the students were assigned a five-minute oral report, to be delivered in French. The second student to stand up in front of the class was a young Hmong man. His chosen topic was a recipe for *la soupe de poisson*: Fish Soup. To prepare Fish Soup, he said, you must have a fish, and in order to have a fish, you have to go fishing. In order to go fishing, you need a hook, and in order to choose the right hook, you need to know whether the fish you are fishing for lives in fresh or salt water, how big it is, and what shape its mouth is. Continuing in this vein for forty-five minutes, the student filled the blackboard with a complexly branching tree of factors and options, a sort of piscatory flowchart, written in French with an overlay of Hmong. He also told several anecdotes about his own fishing experiences. He concluded with a description of how to clean various kinds of fish, how to cut them up, and, finally, how to cook them in broths flavored with various herbs. When the class period ended, he told the other students that he hoped he had provided enough information, and he wished them good luck in preparing Fish Soup in the Hmong manner.

The professor of French who told me this story said, "Fish Soup. That's the essence of the Hmong." The Hmong have a phrase, *hais cuaj txub kaum txub*, which means "to speak of all kinds of things." It

is often used at the beginning of an oral narrative as a way of reminding the listeners that the world is full of things that may not seem to be connected but actually are; that no event occurs in isolation; that you can miss a lot by sticking to the point; and that the storyteller is likely to be rather long-winded. I once heard Nao Kao Lee begin a description of his village in Laos by saying, "It was where I was born and where my father was born and died and was buried and where my father's father died and was buried, but my father's father was born in China and to tell you about that would take all night." If a Hmong tells a fable, for example, about Why Animals Cannot Talk or Why Doodle Bugs Roll Balls of Dung, he is likely to begin with the beginning of the world. (Actually, according to *Dab Neeg Hmoob: Myths, Legends and Folk Tales from the Hmong of Laos*, a bilingual collection edited by Charles Johnson, those two fables go back only to the *second* beginning of the world, the time after the universe turned upside down and the earth was flooded with water and everyone drowned except a brother and sister who married each other and had a child who looked like an egg, whom they hacked into small pieces.) If I were Hmong, I might feel that what happened when Lia Lee and her family encountered the American medical system could be understood fully only by beginning with the *first* beginning of the world. But since I am not Hmong, I will go back only a few hundred generations, to the time when the Hmong were living in the river plains of north-central China.

For as long as it has been recorded, the history of the Hmong has been a marathon series of bloody scrimmages, punctuated by occasional periods of peace, though hardly any of plenty. Over and over again, the Hmong have responded to persecution and to pressures to assimilate by either fighting or migrating—a pattern that has been repeated so many times, in so many different eras and places, that it begins to seem almost a genetic trait, as inevitable in its recurrence as their straight hair or their short, sturdy stature. Most of the conflicts took place in China, to which the prehistoric ancestors of the Hmong were long thought to have migrated from Eurasia, with a stopover of a few millennia in Siberia. Northerly roots might explain the references in Hmong rituals, including some that are still practiced during the New Year celebrations and at funerals, to a Hmong homeland called *Ntuj Khaib Huab*, which (according to a 1924 account by F. M. Savina, a

French apostolic missionary who served in Laos and Tonkin) "was perpetually covered with snow and ice; where the days and the nights each lasted for six months; the trees were scarce and very small; and the people were also very small, and dressed entirely in furs." However, more recent scholars have cast doubt on these tales of Siberian origins, suggesting that Savina's translations were imperfect or that the songs he heard may have described the land of the dead rather than a geographic location. Savina's theory may also have derived from his affection for the Hmong and the consequent impulse, irresistible for a man of his time and place, to believe that they were more European than other Asian peoples, "a special race midway between the white race and the yellow race": in other words, more like him. Not everyone who knew the Hmong wished to draw them closer. In the second century B.C., the Chinese scholar Ssu-ma Ch'ien described them as a race "whose face, eyes, feet, and hands resembled those of other people, but under their armpits they had wings, with which, however, they were unable to fly." As late as the nineteenth century, many Chinese claimed that the Hmong had small tails.

The Chinese called the Hmong the Miao or Meo, which means, depending on which linguistic historian you read, "barbarians," "bumpkins," "people who sound like cats," or "wild uncultivated grasses." In any case, it was an insult. ("Hmong," the name they prefer themselves, is usually said to mean "free men," but some scholars say that, like "Inuit," "Dine," and many other tribal names the world over, it simply means "the people.") The Hmong called the Chinese sons of dogs. The Chinese viewed the Hmong as fearless, uncouth, and recalcitrant. It was a continuing slap in the face that they never evinced any interest in adopting the civilized customs of Chinese culture, preferring to keep to themselves, marry each other, speak their own language, wear their own tribal dress, play their own musical instruments, and practice their own religion. They never even ate with chopsticks. The Hmong viewed the Chinese as meddlesome and oppressive, and rebelled against their sovereignty in hundreds of small and large revolts. Though both sides were equally violent, it was not a symmetrical relationship. The Hmong never had any interest in ruling over the Chinese or anyone else; they wanted merely to be left alone, which, as their later history was also to illustrate, may be the most difficult request any minority can make of a majority culture.

The earliest account of Hmong-Chinese relations concerns a probably mythical, but emotionally resonant, emperor named Hoang-ti, who was said to have lived around 2700 B.C. Hoang-ti decided that the Hmong were too barbaric to be governed by the same laws as everyone else, and that they would henceforth be subject to a special criminal code. Instead of being imprisoned like other offenders, the Hmong who were not executed outright were to have their noses, ears, or testicles sliced off. The Hmong rebelled; the Chinese cracked down; the Hmong rebelled again; the Chinese cracked down again; and after a few centuries of this the Hmong gradually retreated from their rice fields in the valleys of the Yangtze and Yellow rivers, moving to more and more southerly latitudes and higher and higher altitudes. "That is how the Miao* became mountain people," wrote Father Savina. "That is also how they were able to preserve their independence in the midst of other peoples, maintaining intact, along with their language and their customs, the ethnic spirit of their race."

Around A.D. 400, the Hmong succeeded in establishing an independent kingdom in the Honan, Hupeh, and Hunan provinces. Since even among themselves they were (as Father Jean Mottin, a modern French missionary in Thailand, has put it) "allergic to all kind of authority," the power of their kings was limited by a complex system of village and district assemblies. Though the crown was hereditary, each new king was chosen from among the former king's sons by an electorate of all the arms-bearing men in the kingdom. Since the Hmong practiced polygyny, and kings had an especially large number of wives, the pool of candidates was usually ample enough to afford an almost democratically wide choice. The Hmong kingdom lasted for five hundred years before the Chinese managed to crush it. Most of the Hmong migrated again, this time toward the west, to the mountains of Kweichow and Szechuan. More insurrections followed. Some Hmong warriors were known for using poisoned arrows; others went

* Savina was not intentionally insulting the Hmong when he called them by the offensive term "Miao." "Meo" and "Miao" were widely used until the early 1970s, when the scholar Yang Dao successfully campaigned for the general acceptance of "Hmong." More recent scholars have pointed out that although the words "Miao" and "Hmong" have often been used interchangeably, the Chinese also use the word "Miao" to refer to at least two other ethnic minorities.

into battle dressed in copper and buffalo-hide armor, carrying knives clenched between their teeth in addition to the usual spears and shields. Some Hmong crossbows were so big it took three men to draw them. In the sixteenth century, in order to keep the Hmong from venturing outside Kweichow, the Ming dynasty constructed the Hmong Wall, a smaller version of the Great Wall of China that was one hundred miles long, ten feet tall, and manned by armed guards. For a time the Hmong were contained, but not controlled. Gabriel de Magaillans, a Jesuit missionary who traveled through China in the seventeenth century, wrote that they "pay no tribute to the emperor, nor yield him any obedience. . . . The Chinese stand in fear of them; so that after several trials which they have made of their prowess, they have been forced to let them live at their own liberty."

The Chinese tried to "pacify" and "sinicize" the Hmong by telling them that they had to surrender their arms, that they had to wear Chinese clothes, that the men had to cut their hair short, and that they were forbidden to sacrifice buffalos. Those who submitted were called the "Cooked Miao"; those who refused were the "Raw Miao." There were a lot more Raw Miao than cooked ones. In 1730 or thereabouts, hundreds of Hmong warriors killed their wives and children, believing they would fight more fiercely if they had nothing to lose. (It worked for a while. Thus unencumbered, they seized several passes, severing Chinese supply lines, before they themselves were all killed or captured.)

It is, perhaps, no surprise that by the beginning of the nineteenth century, a large number of Hmong decided that they had had enough of China. Not only were they fed up with being persecuted, but their soil was also getting depleted, there was a rash of epidemics, and taxes were rising. Although the majority of the Hmong stayed behind—today there are about five million Hmong in China, more than in any other country—about a half million migrated to Indochina, walking the ridgelines, driving their horses and cattle ahead of them, carrying everything they owned. As was their custom, they went to the highlands, settling first in what are now Vietnam and Laos, and later in Thailand. For the most part, they built their villages in places where no one else wanted to live. But if the local tribes objected or demanded tribute, the Hmong fought back with flintlock blunderbusses, or with their fists, and usually won. Father Mottin quotes an official who said,

"I saw a Meo take my son by the feet and break his spine against the posts of my hut." After the French established control over Indochina in the 1890s, the Hmong rebelled against their extortionate tax system in a series of revolts. One of them, called the Madman's War, which lasted from 1919 to 1921, was led by a messianic figure named Pa Chay, who had a habit of climbing trees so that he could receive his military orders directly from heaven. His followers blew away large numbers of colonial soldiers with ten-foot-long cannons made from tree trunks. Only after the French granted them special administrative status in 1920, acknowledging that the best way to avoid being driven crazy by them was to leave them alone, did the Hmong of Laos, who constituted the largest group outside China, settle down peaceably to several unbroken decades of farming mountain rice, growing opium, and having as little contact as possible with the French, the lowland Lao, or any of the other ethnic groups who lived at lower elevations.

The history of the Hmong yields several lessons that anyone who deals with them might do well to remember. Among the most obvious of these are that the Hmong do not like to take orders; that they do not like to lose; that they would rather flee, fight, or die than surrender; that they are not intimidated by being outnumbered; that they are rarely persuaded that the customs of other cultures, even those more powerful than their own, are superior; and that they are capable of getting very angry. Whether you find these traits infuriating or admirable depends largely on whether or not you are trying to make a Hmong do something he or she would prefer not to do. Those who have tried to defeat, deceive, govern, regulate, constrain, assimilate, intimidate, or patronize the Hmong have, as a rule, disliked them intensely.

On the other hand, many historians, anthropologists, and missionaries (to whom the Hmong have usually been polite, if not always receptive, as long as the proselytizing has not been coercive) have developed a great fondness for them. Father Savina wrote that the Hmong possessed "a bravery and courage inferior to that of no other people," because of which "they have never had a homeland, but neither have they ever known servitude and slavery." William Robert Geddes, an Australian anthropologist, spent most of 1958 and 1959 in Pasamliem, a Hmong village in northern Thailand. (Though more Hmong lived in Laos and Vietnam, most Western observers in the

last half century or so have worked in Thailand because of its stabler political situation.) Geddes did not find his fieldwork easy. The villagers were too proud to sell him food, so he had to transport his supplies by packhorse, nor would they allow themselves to be hired to build him a house, so he had to employ opium addicts from a Thai village lower down the mountain. However, the Hmong eventually won his deep respect. In his book *Migrants of the Mountains*, Geddes wrote:

> The preservation by the Miao of their ethnic identity for such a long time despite their being split into many small groups surrounded by different alien peoples and scattered over a vast geographic area is an outstanding record paralleling in some ways that of the Jews but more remarkable because they lacked the unifying forces of literacy and a doctrinal religion and because the features they preserved seem to be more numerous.

Robert Cooper, a British anthropologist who spent two years studying resource scarcity in four Hmong communities in northern Thailand, described his research subjects as

> polite without fawning, proud but not arrogant. Hospitable without being pushy; discreet respecters of personal liberty who demand only that their liberty be respected in return. People who do not steal or lie. Self-sufficient people who showed no trace of jealousy of an outsider who said he wanted to live like a Hmong yet owned an expensive motorcycle, a tape-recorder, cameras, and who never had to work for a living.

From his post in the Hmong village of Khek Noi, also in northern Thailand, Father Mottin wrote in his *History of the Hmong* (a wonderful book, exuberantly translated from the French by an Irish nun who had once been the tutor to the future king of Thailand, and printed, rather faintly, in Bangkok):

> Though they are but a small people, the Hmong still prove to be great men. What particularly strikes me is to see how this small race has always manged [*sic*] to survive though they often had to face more powerful nations. Let us consider, for example, that the Chinese were 250 times more numerous than they, and yet never found their way to swallow them. The Hmong . . . have never possessed a country of their own, they have never got a king worthy of this name, and yet they have passed through the ages remaining what they have always wished to be, that is to say: free men with a right to live in this world as Hmong. Who would not admire them for that?

One of the recurring characters in Hmong folktales is the Orphan, a young man whose parents have died, leaving him alone to live by his wits. In one story, collected by Charles Johnson, the Orphan offers the hospitality of his humble home to two sisters, one good and one snotty. The snotty one says:

> What, with a filthy orphan boy like you? Ha! You're so ragged you're almost naked! Your penis is dirty with ashes! You must eat on the ground, and sleep in the mud, like a buffalo! I don't think you even have any drink or tobacco to offer us!

The Orphan may not have a clean penis, but he is clever, energetic, brave, persistent, and a virtuoso player of the *qeej*, a musical instrument, highly esteemed by the Hmong, that is made from six curving bamboo pipes attached to a wooden wind chamber. Though he lives by himself on the margins of society, reviled by almost everyone, he knows in his heart that he is actually superior to all his detractors. Charles Johnson points out that the Orphan is, of course, a symbol of the Hmong people. In this story, the Orphan marries the good sister, who is able to perceive his true value, and they prosper and have children. The snotty sister ends up married to the kind of *dab* who lives in a cave, drinks blood, and makes women sterile.

3

The Spirit Catches You and You Fall Down

When Lia was about three months old, her older sister Yer slammed the front door of the Lees' apartment. A few moments later, Lia's eyes rolled up, her arms jerked over her head, and she fainted. The Lees had little doubt what had happened. Despite the careful installation of Lia's soul during the *hu plig* ceremony, the noise of the door had been so profoundly frightening that her soul had fled her body and become lost. They recognized the resulting symptoms as *qaug dab peg*, which means "the spirit catches you and you fall down." The spirit referred to in this phrase is a soul-stealing *dab*; *peg* means to catch or hit; and *qaug* means to fall over with one's roots still in the ground, as grain might be beaten down by wind or rain.

In Hmong-English dictionaries, *qaug dab peg* is generally translated as epilepsy. It is an illness well known to the Hmong, who regard it with ambivalence. On the one hand, it is acknowledged to be a serious and potentially dangerous condition. Tony Coelho, who was Merced's congressman from 1979 to 1989, is an epileptic. Coelho is a popular figure among the Hmong, and a few years ago, some local Hmong men were sufficiently concerned when they learned he suffered from *qaug dab peg* that they volunteered the services of a shaman, a *txiv neeb*, to perform a ceremony that would retrieve Coelho's errant soul. The

Hmong leader to whom they made this proposition politely discouraged them, suspecting that Coelho, who is a Catholic of Portuguese descent, might not appreciate having chickens, and maybe a pig as well, sacrificed on his behalf.

On the other hand, the Hmong consider *qaug dab peg* to be an illness of some distinction. This fact might have surprised Tony Coelho no less than the dead chickens would have. Before he entered politics, Coelho planned to become a Jesuit priest, but was barred by a canon forbidding the ordination of epileptics. What was considered a disqualifying impairment by Coelho's church might have been seen by the Hmong as a sign that he was particularly fit for divine office. Hmong epileptics often become shamans. Their seizures are thought to be evidence that they have the power to perceive things other people cannot see, as well as facilitating their entry into trances, a prerequisite for their journeys into the realm of the unseen. The fact that they have been ill themselves gives them an intuitive sympathy for the suffering of others and lends them emotional credibility as healers. Becoming a *txiv neeb* is not a choice; it is a vocation. The calling is revealed when a person falls sick, either with *qaug dab peg* or with some other illness whose symptoms similarly include shivering and pain. An established *txiv neeb*, summoned to diagnose the problem, may conclude from these symptoms that the person (who is usually but not always male) has been chosen to be the host of a healing spirit, a *neeb*. (*Txiv neeb* means "person with a healing spirit.") It is an offer that the sick person cannot refuse, since if he rejects his vocation, he will die. In any case, few Hmong would choose to decline. Although shamanism is an arduous calling that requires years of training with a master in order to learn the ritual techniques and chants, it confers an enormous amount of social status in the community and publicly marks the *txiv neeb* as a person of high moral character, since a healing spirit would never choose a no-account host. Even if an epileptic turns out not to be elected to host a *neeb*, his illness, with its thrilling aura of the supramundane, singles him out as a person of consequence.

In their attitude toward Lia's seizures, the Lees reflected this mixture of concern and pride. The Hmong are known for the gentleness with which they treat their children. Hugo Adolf Bernatzik, a German ethnographer who lived with the Hmong of Thailand for several years during the 1930s, wrote that the Hmong he had studied regarded a

child as "the most treasured possession a person can have." In Laos, a baby was never apart from its mother, sleeping in her arms all night and riding on her back all day. Small children were rarely abused; it was believed that a *dab* who witnessed mistreatment might take the child, assuming it was not wanted. The Hmong who live in the United States have continued to be unusually attentive parents. A study conducted at the University of Minnesota found Hmong infants in the first month of life to be less irritable and more securely attached to their mothers than Caucasian infants, a difference the researcher attributed to the fact that the Hmong mothers were, without exception, more sensitive, more accepting, and more responsive, as well as "exquisitely attuned" to their children's signals. Another study, conducted in Portland, Oregon, found that Hmong mothers held and touched their babies far more frequently than Caucasian mothers. In a third study, conducted at the Hennepin County Medical Center in Minnesota, a group of Hmong mothers of toddlers surpassed a group of Caucasian mothers of similar socioeconomic status in every one of fourteen categories selected from the Egeland Mother-Child Rating Scale, ranging from "Speed of Responsiveness to Fussing and Crying" to "Delight."

Foua and Nao Kao had nurtured Lia in typical Hmong fashion (on the Egeland Scale, they would have scored especially high in Delight), and they were naturally distressed to think that anything might compromise her health and happiness. They therefore hoped, at least most of the time, that the *qaug dab peg* could be healed. Yet they also considered the illness an honor. Jeanine Hilt, a social worker who knew the Lees well, told me, "They felt Lia was kind of an anointed one, like a member of royalty. She was a very special person in their culture because she had these spirits in her and she might grow up to be a shaman, and so sometimes their thinking was that this was not so much a medical problem as it was a blessing." (Of the forty or so American doctors, nurses, and Merced County agency employees I spoke with who had dealt with Lia and her family, several had a vague idea that "spirits" were somehow involved, but Jeanine Hilt was the only one who had actually asked the Lees what they thought was the cause of their daughter's illness.)

Within the Lee family, in one of those unconscious processes of

selection that are as mysterious as any other form of falling in love, it was obvious that Lia was her parents' favorite, the child they considered the most beautiful, the one who was most extravagantly hugged and kissed, the one who was dressed in the most exquisite garments (embroidered by Foua, wearing dime-store glasses to work her almost microscopic stitches). Whether Lia occupied this position from the moment of her birth, whether it was a result of her spiritually distinguished illness, or whether it came from the special tenderness any parent feels for a sick child, is not a matter Foua and Nao Kao wish, or are able, to analyze. One thing that is clear is that for many years the cost of that extra love was partially borne by her sister Yer. "They blamed Yer for slamming the door," said Jeanine Hilt. "I tried many times to explain that the door had nothing to do with it, but they didn't believe me. Lia's illness made them so sad that I think for a long time they treated Yer differently from their other children."

During the next few months of her life, Lia had at least twenty more seizures. On two occasions, Foua and Nao Kao were worried enough to carry her in their arms to the emergency room at Merced Community Medical Center, which was three blocks from their apartment. Like most Hmong refugees, they had their doubts about the efficacy of Western medical techniques. However, when they were living in the Mae Jarim refugee camp in Thailand, their only surviving son, Cheng, and three of their six surviving daughters, Ge, May, and True, had been seriously ill. Ge died. They took Cheng, May, and True to the camp hospital; Cheng and May recovered rapidly, and True was sent to another, larger hospital, where she eventually recovered as well. (The Lees also concurrently addressed the possible spiritual origins of their children's illnesses by moving to a new hut. A dead person had been buried beneath their old one, and his soul might have wished to harm the new residents.) This experience did nothing to shake their faith in traditional Hmong beliefs about the causes and cures of illness, but it did convince them that on some occasions Western doctors could be of additional help, and that it would do no harm to hedge their bets.

County hospitals have a reputation for being crowded, dilapidated, and dingy. Merced's county hospital, with which the Lees would become all too familiar over the next few years, is none of these. The

MCMC complex includes a modern, 42,000-square-foot wing—it looks sort of like an art moderne ocean liner—that houses coronary care, intensive care, and transitional care units; 154 medical and surgical beds; medical and radiology laboratories outfitted with state-of-the-art diagnostic equipment; and a blood bank. The waiting rooms in the hospital and its attached clinic have unshredded magazines, unsmelly bathrooms, and floors that have been scrubbed to an aseptic gloss. MCMC is a teaching hospital, staffed in part by the faculty and residents of the Family Practice Residency, which is affiliated with the University of California at Davis. The residency program is nationally known, and receives at least 150 applications annually for its six first-year positions.

Like many other rural county hospitals, which were likely to feel the health care crunch before it reached urban hospitals, MCMC has been plagued with financial problems throughout the last twenty years. It accepts all patients, whether or not they can pay; only twenty percent are privately insured, with most of the rest receiving aid from California's Medi-Cal, Medicare, or Medically Indigent Adult programs, and a small (but to the hospital, costly) percentage neither insured nor covered by any federal or state program. The hospital receives reimbursements from the public programs, but many of those reimbursements have been lowered or restricted in recent years. Although the private patients are far more profitable, MCMC's efforts to attract what its administrator has called "an improved payer mix" have not been very successful. (Merced's wealthier residents often choose either a private Catholic hospital three miles north of MCMC or a larger hospital in a nearby city such as Fresno.) MCMC went through a particularly rough period during the late eighties, hitting bottom in 1988, when it had a $3.1 million deficit.

During this same period, MCMC also experienced an expensive change in its patient population. Starting in the late seventies, Southeast Asian refugees began to move to Merced in large numbers. The city of Merced, which has a population of about 61,000, now has just over 12,000 Hmong. That is to say, one in five residents of Merced is Hmong. Because many Hmong fear and shun the hospital, MCMC's patient rolls reflect a somewhat lower ratio, but on any given day there are still Hmong patients in almost every unit. Not only do

the Hmong fail resoundingly to improve the payer mix—more than eighty percent are on Medi-Cal—but they have proved even more costly than other indigent patients, because they generally require more time and attention, and because there are so many of them that MCMC has had to hire bilingual staff members to mediate between patients and providers.

There are no funds in the hospital budget specifically earmarked for interpreters, so the administration has detoured around that technicality by hiring Hmong lab assistants, nurse's aides, and transporters, who are called upon to translate in the scarce interstices between analyzing blood, emptying bedpans, and rolling postoperative patients around on gurneys. In 1991, a short-term federal grant enabled MCMC to put skilled interpreters on call around the clock, but the program expired the following year. Except during that brief hiatus, there have often been no Hmong-speaking employees of any kind present in the hospital at night. Obstetricians have had to obtain consent for cesarean sections or episiotomies using embarrassed teenaged sons, who have learned English in school, as translators. Ten-year-old girls have had to translate discussions of whether or not a dying family member should be resuscitated. Sometimes not even a child is available. Doctors on the late shift in the emergency room have often had no way of taking a patient's medical history, or of asking such questions as Where do you hurt? How long have you been hurting? What does it feel like? Have you had an accident? Have you vomited? Have you had a fever? Have you lost consciousness? Are you pregnant? Have you taken any medications? Are you allergic to any medications? Have you recently eaten? (The last question is of great importance if emergency surgery is being contemplated, since anesthetized patients with full stomachs can aspirate the partially digested food into their lungs, and may die if they choke or if their bronchial linings are badly burned by stomach acid.) I asked one doctor what he did in such cases. He said, "Practice veterinary medicine."

On October 24, 1982, the first time that Foua and Nao Kao carried Lia to the emergency room, MCMC had not yet hired any interpreters, de jure or de facto, for any shift. At that time, the only hospital employee who sometimes translated for Hmong patients was a janitor, a Laotian immigrant fluent in his own language, Lao, which few

Hmong understand; halting in Hmong; and even more halting in English. On that day either the janitor was unavailable or the emergency room staff didn't think of calling him. The resident on duty practiced veterinary medicine. Foua and Nao Kao had no way of explaining what had happened, since Lia's seizures had stopped by the time they reached the hospital. Her only obvious symptoms were a cough and a congested chest. The resident ordered an X ray, which led the radiologist to conclude that Lia had "early bronchiopneumonia or tracheobronchitis." As he had no way of knowing that the bronchial congestion was probably caused by aspiration of saliva or vomit during her seizure (a common problem for epileptics), she was routinely dismissed with a prescription for ampicillin, an antibiotic. Her emergency room Registration Record lists her father's last name as Yang, her mother's maiden name as Foua, and her "primary spoken language" as "Mong." When Lia was discharged, Nao Kao (who knows the alphabet but does not speak or read English) signed a piece of paper that said, "I hereby acknowledge receipt of the instructions indicated above," to wit: "Take ampicillin as directed. Vaporizer at cribside. Clinic reached as needed 383-7007 ten days." The "ten days" meant that Nao Kao was supposed to call the Family Practice Center in ten days for a follow-up appointment. Not surprisingly, since he had no idea what he had agreed to, he didn't. But when Lia had another bad seizure on November 11, he and Foua carried her to the emergency room again, where the same scene was repeated, and the same misdiagnosis made.

On March 3, 1983, Foua and Nao Kao carried Lia to the emergency room a third time. On this occasion, three circumstances were different: Lia was still seizing when they arrived, they were accompanied by a cousin who spoke some English, and one of the doctors on duty was a family practice resident named Dan Murphy. Of all the doctors who have worked at MCMC, Dan Murphy is generally acknowledged to be the one most interested in and knowledgeable about the Hmong. At that time, he had been living in Merced for only seven months, so his interest still exceeded his knowledge. When he and his wife, Cindy, moved to Merced, they had never heard the word "Hmong." Several years later, Cindy was teaching English to Hmong adults and Dan was inviting Hmong leaders to the hospital to tell the

residents about their experiences as refugees. Most impor[t]
Murphys counted a Hmong family, the Xiongs, among their cl[o]
friends. When one of the Xiong daughters wanted to spend the summer working in Yosemite National Park, Chaly Xiong, her father, initially refused because he was afraid she might get eaten by a lion. Dan personally escorted Chaly to Yosemite to verify the absence of lions, and persuaded him the job would do his daughter good. Four months later, Chaly was killed in an automobile accident. Cindy Murphy arranged the funeral, calling around until she found a funeral parlor that was willing to accommodate three days of incense burning, drum beating, and *qeej* playing. She also bought several live chickens, which were sacrificed in the parking lot of the funeral parlor, as well as a calf and a pig, which were sacrificed elsewhere. When Dan first saw the Lees, he instantly registered that they were Hmong, and he thought to himself: "This won't be boring."

Many years later, Dan, who is a short, genial man with an Amish-style beard and an incandescent smile, recalled the encounter. "I have this memory of Lia's parents standing just inside the door to the ER, holding a chubby little round-faced baby. She was having a generalized seizure. Her eyes were rolled back, she was unconscious, her arms and legs were kind of jerking back and forth, and she didn't breathe much—every once in a while, there would be no movement of the chest wall and you couldn't hear any breath sounds. That was definitely anxiety-producing. She was the youngest patient I had ever dealt with who was seizing. The parents seemed frightened, not terribly frightened though, not as frightened as I would have been if it was my kid. I thought it might be meningitis, so Lia had to have a spinal tap, and the parents were real resistant to that. I don't remember how I convinced them. I remember feeling very anxious because they had a real sick kid and I felt a big need to explain to these people, through their relative who was a not-very-good translator, what was going on, but I felt like I had no time, because we had to put an IV in her scalp with Valium to stop the seizures, but then Lia started seizing again and the IV went into the skin instead of the vein, and I had a hard time getting another one started. Later on, when I figured out what had happened, or not happened, on the earlier visits to the ER, I felt good. It's kind of a thrill to find something someone else has missed,

especially when you're a resident and you are looking for excuses to make yourself feel smarter than the other physicians."

Among Dan's notes in Lia's History and Physical Examination record were:

> HISTORY OF PRESENT ILLNESS: The patient is an 8 month, Hmong female, whose family brought her to the emergency room after they had noticed her shaking and not breathing very well for a 20-minute period of time. According to the family the patient has had multiple like episodes in the past, but have never been able to communicate this to emergency room doctors on previous visits secondary to a language barrier. An english speaking relative available tonight, stated that the patient had had intermittent fever and cough for 2–3 days prior to being admitted.
>
> FAMILY & SOCIAL HISTORY: Unobtainable secondary to language difficulties.
>
> NEUROLOGICAL: The child was unresponsive to pain or sound. The head was held to the left with intermittent tonic-clonic [first rigid, then jerking] movements of the upper extremities. Respirations were suppressed during these periods of clonic movement. Grunting respirations persisted until the patient was given 3 mg. of Valium I.V.

Dan had no way of knowing that Foua and Nao Kao had already diagnosed their daughter's problem as the illness where the spirit catches you and you fall down. Foua and Nao Kao had no way of knowing that Dan had diagnosed it as epilepsy, the most common of all neurological disorders. Each had accurately noted the same symptoms, but Dan would have been surprised to hear that they were caused by soul loss, and Lia's parents would have been surprised to hear that they were caused by an electrochemical storm inside their daughter's head that had been stirred up by the misfiring of aberrant brain cells.

Dan had learned in medical school that epilepsy is a sporadic malfunction of the brain, sometimes mild and sometimes severe, sometimes progressive and sometimes self-limiting, which can be traced to oxygen deprivation during gestation, labor, or birth; a head injury; a tumor; an infection; a high fever; a stroke; a metabolic disturbance; a

drug allergy; a toxic reaction to a poison. Sometimes the source is obvious—the patient had a brain tumor or swallowed strychnine or crashed through a windshield—but in about seven out of ten cases, the cause is never determined. During an epileptic episode, instead of following their usual orderly protocol, the damaged cells in the cerebral cortex transmit neural impulses simultaneously and chaotically. When only a small area of the brain is involved—in a "focal" seizure—an epileptic may hallucinate or twitch or tingle but retain consciousness. When the electrical disturbance extends to a wide area—in a "generalized" seizure—consciousness is lost, either for the brief episodes called petit mal or "absence" seizures, or for the full-blown attacks known as grand mal. Except through surgery, whose risks consign it to the category of last resort, epilepsy cannot be cured, but it can be completely or partially controlled in most cases by anticonvulsant drugs.

The Hmong are not the only people who might have good reason to feel ambivalent about suppressing the symptoms. The Greeks called epilepsy "the sacred disease." Dan Murphy's diagnosis added Lia Lee to a distinguished line of epileptics that has included Søren Kierkegaard, Vincent van Gogh, Gustave Flaubert, Lewis Carroll, and Fyodor Dostoyevsky, all of whom, like many Hmong shamans, experienced powerful senses of grandeur and spiritual passion during their seizures, and powerful creative urges in their wake. As Dostoyevsky's Prince Myshkin asked, "What if it is a disease? What does it matter that it is an abnormal tension, if the result, if the moment of sensation, remembered and analysed in a state of health, turns out to be harmony and beauty brought to their highest point of perfection, and gives a feeling, undivined and undreamt of till then, of completeness, proportion, reconciliation, and an ecstatic and prayerful fusion in the highest synthesis of life?"

Although the inklings Dan had gathered of the transcendental Hmong worldview seemed to him to possess both power and beauty, his own view of medicine in general, and of epilepsy in particular, was, like that of his colleagues at MCMC, essentially rationalist. Hippocrates' skeptical commentary on the nature of epilepsy, made around 400 B.C., pretty much sums up Dan's own frame of reference: "It seems to me that the disease is no more divine than any other. It has a natural cause just as other diseases have. Men think it is divine merely because they don't understand it. But if they called everything

divine which they do not understand, why, there would be no end of divine things."*

Lia's seizure was a grand mal episode, and Dan had no desire to do anything but stop it. He admitted her to MCMC as an inpatient. Among the tests she had during the three days she spent there were a spinal tap, a CT scan, an EEG, a chest X ray, and extensive blood work. Foua and Nao Kao signed "Authorization for and Consent to Surgery or Special Diagnostic or Therapeutic Procedures" forms, each several hundred words long, for the first two of these. It is not known whether anyone attempted to translate them, or, if so, how "Your physician has requested a brain scan utilizing computerized tomography" was rendered in Hmong. None of the tests revealed any apparent cause for the seizures. The doctors classified Lia's epilepsy as "idiopathic": cause unknown. Lia was found to have consolidation in her right lung, which this time was correctly diagnosed as aspiration pneumonia resulting from the seizure. Foua and Nao Kao alternated nights at the hospital, sleeping in a cot next to Lia's bed. Among the Nurse's Notes for Lia's last night at the hospital were: "0001. Skin cool and dry to touch, color good & pink. Mom is with babe at this time & is breastfeeding. Mom informed to keep babe covered with a blanket for the babe is a little cool." "0400. Babe resting quietly

* Despite this early attempt by Hippocrates (or perhaps by one of the anonymous physicians whose writings are attributed to Hippocrates) to remove the "divine" label, epilepsy continued, more than any other disease, to be ascribed to supernatural causes. The medical historian Owsei Temkin has noted that epilepsy has held a key position historically in "the struggle between magic and the scientific conception." Many treatments for epilepsy have had occult associations. Greek magicians forbade epileptics to eat mint, garlic, and onion, as well as the flesh of goats, pigs, deer, dogs, cocks, turtledoves, bustards, mullets, and eels; to wear black garments and goatskins; and to cross their hands and feet: taboos that were all connected, in various ways, with chthonic deities. Roman epileptics were advised to swallow morsels cut from the livers of stabbed gladiators. During the Middle Ages, when epilepsy was attributed to demonic possession, treatments included prayer, fasting, wearing amulets, lighting candles, visiting the graves of saints, and writing the names of the Three Wise Men with blood taken from the patient's little finger. These spiritual remedies were far safer than the "medical" therapies of the time—still practiced as late as the seventeenth century—which included cauterizing the head with a hot iron and boring a hole in the skull to release peccant vapors.

with no acute distress noted. Mom breast feeds off & on." "0600. Sleeping." "0730. Awake, color good. Mother fed." "1200. Held by mother."

Lia was discharged on March 11, 1983. Her parents were instructed, via an English-speaking relative, to give her 250 milligrams of ampicillin twice a day, to clear up her aspiration pneumonia, and twenty milligrams of Dilantin elixir, an anticonvulsant, twice a day, to suppress any further grand mal seizures.

4

Do Doctors Eat Brains?

In 1982, Mao Thao, a Hmong woman from Laos who had resettled in St. Paul, Minnesota, visited Ban Vinai, the refugee camp in Thailand where she had lived for a year after her escape from Laos in 1975. She was the first Hmong-American ever to return there, and when an officer of the United Nations High Commissioner for Refugees, which administered the camp, asked her to speak about life in the United States, 15,000 Hmong, more than a third of the population of Ban Vinai, assembled in a soccer field and questioned her for nearly four hours. Some of the questions they asked her were: Is it forbidden to use a *txiv neeb* to heal an illness in the United States? Why do American doctors take so much blood from their patients? After you die, why do American doctors try to open up your head and take out your brains? Do American doctors eat the livers, kidneys, and brains of Hmong patients? When Hmong people die in the United States, is it true that they are cut into pieces and put in tin cans and sold as food?

The general drift of these questions suggests that the accounts of the American health care system that had filtered back to Asia were not exactly enthusiastic. The limited contact the Hmong had already had with Western medicine in the camp hospitals and clinics had done little to instill confidence, especially when compared to the experiences

with shamanistic healing to which they were accustomed. A *txiv neeb* might spend as much as eight hours in a sick person's home; doctors forced their patients, no matter how weak they were, to come to the hospital, and then might spend only twenty minutes at their bedsides. *Txiv neebs* were polite and never needed to ask questions; doctors asked many rude and intimate questions about patients' lives, right down to their sexual and excretory habits. *Txiv neebs* could render an immediate diagnosis; doctors often demanded samples of blood (or even urine or feces, which they liked to keep in little bottles), took X rays, and waited for days for the results to come back from the laboratory—and then, after all that, sometimes they were unable to identify the cause of the problem. *Txiv neebs* never undressed their patients; doctors asked patients to take off all their clothes, and sometimes dared to put their fingers inside women's vaginas. *Txiv neebs* knew that to treat the body without treating the soul was an act of patent folly; doctors never even mentioned the soul. *Txiv neebs* could preserve unblemished reputations even if their patients didn't get well, since the blame was laid on the intransigence of the spirits rather than the competence of the negotiators, whose stock might even rise if they had had to do battle with particularly dangerous opponents; when doctors failed to heal, it was their own fault.

To add injury to insult, some of the doctors' procedures actually seemed more likely to threaten their patients' health than to restore it. Most Hmong believe that the body contains a finite amount of blood that it is unable to replenish, so repeated blood sampling, especially from small children, may be fatal. When people are unconscious, their souls are at large, so anesthesia may lead to illness or death. If the body is cut or disfigured, or if it loses any of its parts, it will remain in a condition of perpetual imbalance, and the damaged person not only will become frequently ill but may be physically incomplete during the next incarnation; so surgery is taboo. If people lose their vital organs after death, their souls cannot be reborn into new bodies and may take revenge on living relatives; so autopsies and embalming are also taboo. (Some of the questions on the Ban Vinai soccer field were obviously inspired by reports of the widespread practice of autopsy and embalming in the United States. To make the leap from hearing that doctors removed organs to believing that they ate them was probably no crazier than to assume, as did American doctors,

that the Hmong ate human placentas—but it was certainly scarier.)

The only form of medical treatment that was gratefully accepted by at least some of the Hmong in the Thai camps was antibiotic therapy, either oral or by injection. Most Hmong have little fear of needles, perhaps because some of their own healers (not *txiv neebs*, who never touch their patients) attempt to release fevers and toxicity through acupuncture and other forms of dermal treatment, such as massage; pinching; scraping the skin with coins, spoons, silver jewelry, or pieces of bamboo; applying a heated cup to the skin; or burning the skin with a sheaf of grass or a wad of cotton wool. An antibiotic shot that could heal an infection almost overnight was welcomed. A shot to immunize someone against a disease he did not yet have was something else again. In his book *Les naufragés de la liberté*, the French physician Jean-Pierre Willem, who worked as a volunteer in the hospital at the Nam Yao camp, related how during a typhoid epidemic, the Hmong refugees refused to be vaccinated until they were told that only those who got shots would receive their usual allotments of rice —whereupon 14,000 people showed up at the hospital, including at least a thousand who came twice in order to get seconds.

When Foua Yang and Nao Kao Lee brought their three sick children to the hospital at Mae Jarim, they were engaging in behavior that many of the other camp inhabitants would have considered positively aberrant. Hospitals were regarded not as places of healing but as charnel houses. They were populated by the spirits of people who had died there, a lonesome and rapacious crew who were eager to swell their own ranks. Catherine Pake, a public health nurse who spent six months working at Phanat Nikhom (a camp where refugees from Laos, Vietnam, and Cambodia came for their final "processing" before they were sent to a country of permanent asylum), concluded from a study of the hospital log that "in comparison to refugees of other ethnic groups, the Hmong have the lowest per capita rate of visits." (Pake also discovered, not coincidentally, that the Hmong had an extremely "high utilization rate" of indigenous healing arts: shamanism, dermal treatments, herbalism. She published an article in the *Journal of Ethnobiology* identifying twenty medicinal plants she had collected under the tutelage of Hmong herbalists, which, in various forms—chopped, crushed, dried, shredded, powdered, decocted, infused with hot water, infused with cold water, mixed with ashes, mixed with sulphur, mixed with egg, mixed with chicken—were indicated for burns, fever, weakness, poor vision, broken bones, stomachaches, painful urination, prolapsed uterus, insufficient breast milk, arthritis, anemia, tuberculosis, rabies, scabies, gonorrhea, dysentery, constipation, impotence, and attacks by a *dab ntxaug*, a spirit who lives in the jungle and causes epidemics when he is disturbed. In this last case, the plant, *Jatropha curcas*, is crushed and its oil left in a cup, to be consumed not by the patient but by the *dab*.)

Wendy Walker-Moffat, an educational consultant who spent three years teaching and working on nutritional and agricultural projects in Phanat Nikhom and Ban Vinai, suggests that one reason the Hmong avoided the camp hospitals is that so many of the medical staff members were excessively zealous volunteers from Christian charitable organizations. "They were there to provide medical aid, but they were also there—though not overtly—to convert people," Walker-Moffat told me. "And part of becoming converted was believing in Western medicine. I'll never forget one conversation I overheard when I was working in the hospital area at Ban Vinai. A group of doctors and nurses were talking to a Hmong man whom they had converted and ordained as a Protestant minister. They had decided that in order to get the Hmong to come into the hospital they were going to allow a traditional healer, a shaman, to practice there. I knew they all thought shamanism was witch-doctoring. So I heard them tell this Hmong minister that if they let a shaman work in the medical center he could only give out herbs, and not perform any actual work with the spirits. At this point they asked the poor Hmong minister, 'Now *you* never go to a shaman, do you?' He was a Christian convert, he knew you cannot tell a lie, so he said, 'Well, yes, I do.' But then their reaction was so shocked that he said, 'No, no, no, I've never been. I've just heard that *other* people go.' What they didn't realize was that—to my knowledge, at least—no Hmong is ever fully converted."

In 1985, the International Rescue Committee assigned Dwight Conquergood, a young ethnographer with a special interest in shamanism and performance art, to design an environmental health program for Ban Vinai. He later wrote:

> I heard horror story after horror story from the refugees about people who went to the hospital for treatment, but before being admitted had

> their spirit-strings cut from their wrists by a nurse because "the strings were unsanitary and carried germs." Doctors confidently cut off neck-rings that held the life-souls of babies intact. Instead of working in cooperation with the shamans, they did everything to disconfirm them and undermine their authority. . . . Is it any wonder that the Hmong community regarded the camp hospital as the last choice of available health care options? In the local hierarchy of values, consulting a shaman or herbalist, or purchasing medicine available in the Thai market just outside the entrance to the camp, was much preferred and more prestigious than going to the camp hospital. The refugees told me that only the very poorest people who had no relatives or resources whatsoever would subject themselves to the camp hospital treatment. To say that the camp hospital was underutilized would be an understatement.

Unlike the other camp volunteers, who commuted from an expatriate enclave an hour away, Conquergood insisted on living in Ban Vinai, sharing the corner of a thatched hut with seven chickens and a pig. His first day in the camp, Conquergood noticed a Hmong woman sitting on a bench, singing folk songs. Her face was decorated with little blue moons and golden suns, which he recognized as stickers the camp clinic placed on medication bottles to inform illiterate patients whether the pills should be taken morning or night. The fact that Conquergood considered this a delightful example of creative costume design rather than an act of medical noncompliance suggests some of the reasons why the program he designed turned out to be the most (indeed, possibly the only) completely successful attempt at health care delivery Ban Vinai had ever seen.

Conquergood's first challenge came after an outbreak of rabies among the camp dogs prompted a mass dog-vaccination campaign by the medical staff, during which the Ban Vinai inhabitants failed to bring in a single dog to be inoculated. Conquergood was asked to come up with a new campaign. He decided on a Rabies Parade, a procession led by three important characters from Hmong folktales—a tiger, a chicken, and a *dab*—dressed in homemade costumes. The cast, like its audience, was one hundred percent Hmong. As the parade snaked through the camp, the tiger danced and played the *qeej*, the *dab* sang and banged a drum, and the chicken (chosen for this crucial role because of its traditional powers of augury) explained the etiology of rabies through a bullhorn. The next morning, the vaccination stations were so besieged by dogs—dogs carried in their owners' arms, dogs dragged on rope leashes, dogs rolled in on two-wheeled pushcarts—that the health workers could hardly inoculate them fast enough. Conquergood's next production, a sanitation campaign in which a parade of children led by Mother Clean (a huge, insanely grinning figure on a bamboo frame) and the Garbage Troll (dressed in ragged clothes plastered with trash) sang songs about latrine use and refuse disposal, was equally well received.

During Conquergood's five months in Ban Vinai, he himself was successfully treated with Hmong herbs for diarrhea and a gashed toe. When he contracted dengue fever (for which he also sought conventional medical treatment), a *txiv neeb* informed him that his homesick soul had wandered back to Chicago, and two chickens were sacrificed to expedite its return. Conquergood considered his relationship with the Hmong to be a form of barter, "a productive and mutually invigorating dialog, with neither side dominating or winning out." In his opinion, the physicians and nurses at Ban Vinai failed to win the cooperation of the camp inhabitants because they considered the relationship one-sided, with the Westerners holding all the knowledge. As long as they persisted in this view, Conquergood believed that what the medical establishment was offering would continue to be rejected, since the Hmong would view it not as a gift but as a form of coercion.

5

Take as Directed

Between the ages of eight months and four and a half years, Lia Lee was admitted to MCMC seventeen times and made more than a hundred outpatient visits to the emergency room and to the pediatric clinic at the Family Practice Center. "Hmong ♀," read the admission notes. Then, "Hmong ♀ well known to this facility." Then, "Hmong ♀ very well known to this facility." Sometimes instead of "Hmong" the notes say "H'mond" or "Mong" or, in one note transcribed from a tape dictated by a resident, "Mongoloid"—an attempt by a tired typist to make sense of a strange syllable not to be found in any medical dictionary. Under "How Arrived," the notes always say "Via mo's arms"; under "Initial Diagnostic Impression," always "seizure disorder of unknown etiology," and sometimes fever and pneumonia and infections of the middle ear; under "Insurance Coverage," always Medi-Cal; under amount paid by patient, always zero. Almost all the admission notes contain the phrase "language barrier." On one assessment form, a nurse's aide with a Hispanic surname has written, "unable to obtain parient speak no english." On another form, in the space marked "Communication Problems," another nurse has summed up the situation with a single word: "Hmong."

Foua and Nao Kao always knew exactly when a seizure was coming, because Lia knew. The aura, a sense of premonition common to epileptics and sufferers of migraine and angina, can take many forms, from mildly peculiar sensations—sudden tastes or smells, tingling, flushing, *déjà vu*, *jamais vu* (the feeling that an experience is utterly unfamiliar)—to mortal terror. Physicians in the eighteenth century called the frightening auras *angor animi*, "soul anguish," a concept any Hmong might recognize. Before Lia fell, she would run to her parents to be hugged. She also demanded plenty of hugs from them when she was feeling fine, but they recognized these occasions as different because she had a strange, scared expression, and they would gently pick her up and lay her on the mattress they kept for this purpose on the floor of their living room (which was otherwise unfurnished). Sometimes there was twitching on one side of her body, usually the right. Sometimes she had staring spells. Sometimes she seemed to hallucinate, rapidly scanning the air and reaching for invisible objects. As Lia got older, the abnormal electrical activity spread to larger and larger areas of her brain and triggered more frequent grand mal episodes. As she lay face up, her back would arch so violently that only her heels and the back of her head would touch the mattress, and then, after a minute or so of rigid muscle contractions, her arms and legs would start to thrash. During the first phase, her respiratory muscles contracted along with the rest of her body, and she would often stop breathing. Her lips and nail beds turned blue. Sometimes she gave high-pitched gasps, foamed at the mouth, vomited, urinated, or defecated. Sometimes she had several seizures in a row; between them, she would tense, point her toes, and cry a strange deep cry.

In the most serious episodes, Lia would continue seizing and seizing without regaining consciousness. This condition, called "status epilepticus" when it lasts for twenty minutes or longer, is what the doctors in the MCMC emergency room feared most. Lia usually remained in "status" until massive doses of anticonvulsant medication could be administered intravenously. Inserting a needle into the vein of a baby who is having convulsions is like shooting, or trying to shoot, a very small moving target. While the hapless young resident who happened to be on call maneuvered the needle, he or she was always acutely aware that as each second ticked away during the phases of respiratory arrest, Lia's brain was being deprived of oxygen. When I asked one nurse whether this caused brain damage, he said, "If you

want to know what a five-minute seizure is like, go stick your head in a bucket of water for five minutes and take some deep breaths." Over the course of several years, Lia was treated at least once, and sometimes many times, by each of MCMC's residents. Frightening as it was to be on duty when Lia was brought in at 3:00 a.m., there was probably no other group of family practice residents in the United States who by the end of their three-year program were so familiar with the management of pediatric grand mal seizures.

The residents were merely the first line of defense. Every time Lia came to the emergency room, either Neil Ernst or Peggy Philp, the two supervising pediatricians who served on the faculty of the family practice residency program, was paged and, no matter how late it was, drove to the hospital (a trip that could be accomplished, at just under the speed limit, in seven minutes). Peggy Philp was the physician Dan Murphy consulted during Lia's first admission to MCMC. The note she wrote six days after Lia's discharge read, in part:

> This is a very interesting young infant who presents with a history of right focal seizures. One leading to a grand mal seizure. I feel that probably the grand mal seizure caused an aspiration pneumonia and hence apnea, causing her extreme distress when she showed up in the Emergency Room on the day of admission. The child has apparently done well on her Dilantin, although she has continued to have some right focal seizures. . . . My feeling is that this child probably has some form of benign focal seizures of infancy. These are not especially common, but can often be quite benign in nature. Since there is apparently some chance that these will generalize, it is probably worth while to keep the child on Dilantin therapy to suppress a grand mal seizure. I would check the Dilantin level to make sure that it remains therapeutic. . . . I think that the prognosis for this child's intellectual development remains good.

Looking back on this optimistic document several years later, Peggy explained, "Most epileptics are controlled relatively easily by seizure medications. Lia's disorder turned out to be much more severe than what you usually see in classic epilepsy." Lia's chart eventually grew to five volumes, longer than the chart of any other child who has ever been admitted to MCMC, and weighed thirteen pounds eleven ounces, considerably more than Lia weighed when she was born there. Neil and Peggy once went through a photocopy of it with

me. Over a period of several evenings, the two doctors worked with the same briskness and efficiency they would have brought to a patient's diagnostic examination, arranging the thousands of pages in neat stacks, rapidly discarding any they deemed irrelevant, never skipping over—in fact, often specifically pointing out—details that failed to put them in the best possible light, and stopping every once in a while to laugh ruefully at the chart's many errors. (The errors were invariably made by transcribers, nurses, or other physicians; their own contributions were flawless and usually even legible.) " 'She was seen to have lice coming out of her nose.' Lice. That can't be right. Ice? Mice? Rice! Shoot, that's what it is, rice!" Sometimes Neil would stop and stare at a page, often one that seemed anesthetically dull to me, and shake his head and sigh and say, "Oh God, Lia." When we looked through the records of Lia's first visits to the emergency room, he started to flip the pages back and forth with angry little slapping motions. He had forgotten that she had had epileptic seizures for five months before they were diagnosed and medicated, and was wondering in retrospect whether the course of her life might have been different if his hospital had offered her optimal medical care from the beginning.

Neil Ernst and Peggy Philp are married to each other. They alternate call nights, and each prayed that when a Lia Lee call came, it would be the other one's turn to roll out of bed. Neil and Peggy are both the children of physicians, both high school valedictorians, both Phi Beta Kappa graduates of Berkeley. They met when they were nineteen and eighteen, two tall, good-looking, athletic premed students who recognized in each other the combination of idealism and workaholism that had simultaneously contributed to their successes and set them apart from most of their peers. By the time their lives intersected with Lia's, they shared a practice and a half, as well as an office, a beeper, and a byline on the articles they had published in medical journals. Neil's curriculum vitae, which was flush with academic and professional honors, was the only one I have ever seen that noted Marital Status and Children first. Their schedules were arranged in such a way that one of them was always home in the afternoon when their two sons got out of school. Every morning, the alarm buzzed at 5:45. If it was Monday, Wednesday, or Friday, Neil got up and ran eight miles. If it was Tuesday, Thursday, or Sunday, Peggy

got up and ran eight miles. They alternated Saturdays. Their runs were the only time either of them was entirely alone for more than a few minutes, and they never skipped or traded a morning, even if they had been up most of the night on call at MCMC. "I am a fairly driven and compulsive kind of person," Neil told me one night in the living room of their extremely neat ranch-style house, the care of which was evenly split between them. Peggy was on call at the hospital. "Peggy is very similar to me. We get along real well. *Real, real* well. Medically, we complement each other. My strengths are infections, asthma, and allergies. Peggy is strong in hematology and she's better than I am in child development. When you're confronted with a difficult decision, it's nice to talk to someone whose judgment you respect. Am I thinking okay? Would you offer anything else? Can I do anything else? If I feel like a dumbshit I can be a dumbshit with her. We don't have to impress each other. If she was not in my life it would . . . well, take a while for me to be able to function."

I once asked Teresa Callahan and Benny Douglas—a pair of married family physicians who trained as residents under Neil Ernst and Peggy Philp and who, like their mentors, now share a practice—what they thought of them. Teresa said, "It's hard to perceive them separately." Benny said, "I mean, like, Neil apostrophe n apostrophe Peggy is the way we think of them. Neil 'n' Peggy know everything and they never make mistakes. They are perfect. If we ever had problems all we had to do was call Neil 'n' Peggy and they would figure it out." Teresa said, "Neil 'n' Peggy are controlled, Neil especially, almost to a fault. I have even heard him say, about getting angry or crying, that he just doesn't feel comfortable doing things like that. But that doesn't mean he isn't compassionate. He prides himself on establishing a good rapport with his clinic patients, including some very difficult ones, some Spanish speaking, and most patients accept what he and Peggy say as gospel and do whatever they say. Few other people I know would have gone to the lengths they did to provide good medical care to Lia. They were always thinking about her. Whenever they had to go away, they'd tell all the residents, 'Now if this little fat Hmong girl comes in seizing. . . .' "

Lia was indeed fat. Her Physical Growth chart shows that although her height usually hovered around the fifth percentile for her age (not unusual for a Hmong child), her weight climbed as high as the seventy-fifth percentile. Her thick subcutaneous padding compounded the challenges that awaited the doctors in the emergency room. Neil Ernst wrote in a pediatric clinic note that in addition to her seizure disorder, "Lia's other problem, which is of considerable concern, is the fact that she is quite overweight, which makes intravenous access during the time of seizures quite difficult. Considerable effort has gone into weight control in this child. The father apparently likes Lia the way she is and is somewhat resistant to this problem." (In Laos, where food was often scarce, a plump Hmong child was perceived as healthy and especially well cared for.)

A vein hidden under fat is hard to palpate. Like a drug user who loses veins after repeated needle sticks, Lia eventually lost the antecubital veins in both forearms and the saphenous vein above her left ankle after doctors frantically searching for needle placement cut them open and tied them off. During most of her hospitalizations, the arm or leg with the IV line was bandaged to a board, and sometimes she was secured to her crib as well. "Lia's IVs were precious," explained Neil. "The less she moved, the longer the IVs would last." One Nurse's Note reads: "2400. IV infusing R antecubital space with signs of infiltration @ 30cc/hr via pump. Father here. Soft restraint to L arm. 0015. Father had untied restraint & placed child on cot on floor. Returned child to bed, soft restraint to R arm. Tried to explain to father reason but difficult due to communication barrier."

Nao Kao did not understand why the nurses had tied up his daughter. His confidence in their ability to care for Lia was further strained the morning after this note was written, when he left the hospital at 4:00 a.m. to catch two or three hours of sleep at home and returned at 7:30 to find that Lia had a bump on her forehead the size of a goose egg, the result of having fallen out of her crib during his brief absence. Not only had Lia gotten hurt while under the supervision of people who claimed to know more than the Lees about how to keep her healthy, but those people had then responded to the accident in a manner that, from the Lees' point of view, was inexplicably sadistic. Foua and Nao Kao believed the best way to keep Lia safe and content, especially when she was ill or in pain, was to have her sleep next to them, as she always did at home, so they could immediately comfort

her whenever she cried. The nurses, however, decided to guard against future falls by rigging a net over Lia's crib and caging her inside, out of reach of her parents' arms.

"A hospital is a scary place for any parent," Vonda Crouse, a physician at Valley Children's Hospital in Fresno who is on the faculty of the Merced family practice residency program, told me. "You see people wake up your sleeping child to take their blood pressure, take their temperature, check their pulse rate, and count respirations. You see them put a bag on your kid to measure the output of urine and stool. When your child is in the hospital, suddenly somebody else is feeding them, somebody else is changing their pants, somebody else is deciding how and when they will be bathed. It takes all the autonomy of being a parent away, even for folks who have had a lot of medical experience. It would be that much harder if you were from another culture and didn't understand the purpose of all these things."

Aside from the time Lia fell on her head, one or another of her parents was almost always present around the clock during her hospital stays. Some typical Nurse's Notes: "Does not like to be separated from mo; relaxes when held by mo." "Is quiet as long as mom holds her, otherwise screams most of the time." "Child is happy & babbling, plays with toys. Mom here. Babe content." "Being carried papoose style by fa." "Mother here & breast feeds eagerly. Cruises sides of crib. Makes baby sounds." "Awake, walking around to the hallway with the father then returned to the room. Father trying to put her back to sleep." "Baby was in wagon sitting up and had generalized seizure lasting 1 min. Father grabbed her right away no injuries." "Mother holding. No seizures this shift. Up in mom's arms, waves 'Bye Bye.' "

The MCMC nursing staff came to know Lia well—better, in fact, than most of them would have wished. After she was old enough to walk, whenever she was well enough to get out of bed she ran up and down the corridor in the pediatric unit, banging on doors, barging into the rooms of other sick children, yanking open the drawers in the nursing station, snatching pencils and hospital forms and prescription pads and throwing them on the floor. "You'd hear that Lia was in the ER," recalled Sharon Yates, a nurse's aide. "Lia, Lia. Oh please, you'd say, don't let her up! But up she'd come." Evelyn Marciel, a nurse, said, "Lia was a pretty girl, soft and cute and fast. Her mother wouldn't wean her and she was real dependent on the breast. She was

a little Houdini. She could get out of anything, and she'd hurt herself even if she had her wrists bound up, so you could never let her alone." "Her attention span was real short," said Gloria Rodriguez, a nurse. "We taught her to say bye, play patty-cake, smile, and clap hands. But she always wanted to be held, she always put her hands up to be carried because that's what her parents did. With other Hmong families the sons are the ones who are loved. Hmong fathers say, Girl okay if die, want many boy. But this family, they wanted so much for her to live, they just adored her." Many of the doctors remember Lia with affection because, unlike most of their pediatric patients, she was always physically demonstrative. "She liked skin," recalled Kris Hartwig, one of the residents who took care of Lia. "Even when I was trying to start an intravenous line, she'd be going pick, pick, pick at my arm. When you asked for a hug you could always get one from Lia." Peggy Philp said, "A lot of little kids, after being through all that, would just cry and hide in a corner or something, but Lia was very bold and she wasn't afraid of you. So you kind of liked her because she was a character, even though you hated her because she was so frustrating and she caused you so much grief."

Lia hated swallowing her medications. Some Nurse's Notes: "Meds given but did not like." "Tries to spit out Phenobarb when given. Lips pursed tightly to prevent this med given." "Fought taking medicine even crushed Phenobarb tablets in applesauce. Spits well." "Pt. very good at spitting out meds, given slowly with arms held & mouth puckered open." "Spit out popsicle with medicine crushed in, had to repeat dose with strawberry ice cream this time taken well." The Lees had an even harder time persuading Lia to take her medications than the nurses did, since they were reluctant to restrain her arms or force anything down her throat. And even when Lia was cooperative, Foua and Nao Kao were often uncertain about exactly what they were supposed to give her. Over time, her drug regimen became so complicated and underwent so many revisions that keeping track of it would have been a monumental task even for a family that could read English. For the Lees, it proved to be utterly confounding.

The anticonvulsant medication originally prescribed by Peggy Philp was Dilantin, which is commonly used to control grand mal seizures. Three weeks after her first MCMC admission, after Lia had a seizure in the hospital waiting room that appeared to be triggered

by a fever, Peggy changed the prescription to phenobarbital, which controls febrile seizures better than Dilantin. Lia seized several times during the next two weeks, so since neither drug appeared to work adequately alone, Peggy then prescribed them both simultaneously. Consulting neurologists later prescribed two other anticonvulsants, Tegretol (which was originally to be used along with both Dilantin and phenobarbital, and then just with phenobarbital) and Depakene (which was to be used in place of all the previous anticonvulsants). Because lung and ear infections frequently accompanied Lia's seizures, antibiotics, antihistamines, and bronchodilating drugs were also prescribed from time to time.

By the time she was four and a half, Lia's parents had been told to give her, at various times, Tylenol, ampicillin, amoxicillin, Dilantin, phenobarbital, erythromycin, Ceclor, Tegretol, Benadryl, Pediazole, Vi-Daylin Multivitamins with Iron, Alupent, Depakene, and Valium. Because these medications were prescribed in varying combinations, varying amounts, and varying numbers of times a day, the prescriptions changed twenty-three times in less than four years. Some of the drugs, such as vitamins and anticonvulsants, were supposed to be given every day no matter how Lia was feeling, and when they ran out, her parents were supposed to renew the prescriptions; some, such as antibiotics, were supposed to be given for a specific period of time, and though they were prescribed only when Lia displayed certain symptoms, the prescriptions were to be finished (but not renewed) even if those symptoms disappeared; antifebrile medications, prescribed in the hope of warding off fever-triggered seizures before they happened, were supposed to be administered only if Lia had a temperature, a plan that might have worked better if her parents had been able to read a thermometer. Several of the medications were available in different forms, and were sometimes prescribed as elixirs (all of which were pink or red and came in round bottles) and sometimes as tablets (almost all of which were white and came in round bottles). Foua and Nao Kao, of course, had no idea what the labels said. Even if a relative or the hospital janitor was on hand to translate when a bottle was handed to the Lees, they had no way of writing down the instructions, since they are illiterate in Hmong as well as English; and because the prescriptions changed so frequently, they often forgot what the doctors told them. Measuring the correct doses posed additional

problems. Liquids were difficult because the Lees could not read the markings on medicine droppers or measuring spoons. Pills were often no easier. At one point, when Lia was two, she was supposed to be taking four different medications in tablet form twice a day, but because each of the pills contained an adult dose, her parents were supposed to cut each of the tablets into fractions; and because Lia disliked swallowing the pills, each of those fractions had to be pulverized with a spoon and mixed with food. If she then ate less than a full helping of the adulterated food, there was no way to know how much medicine she had actually consumed.

At first, it did not occur to Lia's doctors that the Lees would fail to administer her medications correctly. The first few prescriptions simply read "Take as directed." In May of 1983, two months after Lia's first hospital admission, when a blood test showed a subtherapeutic level of phenobarbital in Lia's system, Peggy Philp assumed that the prescribed amount was being given, and raised the dosage. The next month, when the levels tested low again, she began to suspect that when Lia's mother said she was giving the medicines as prescribed, she was either confused or lying. This was a dismaying realization. The only way to determine the optimal type and amount of anticonvulsant medications for Lia was to observe the level of her seizure activity and repeatedly test the medication level in her blood, but the test results were inconclusive unless the doctors knew exactly what was going into her system.

"Lia continued to have seizures," said Peggy. "But was she having those seizures because she didn't have enough phenobarbital in her blood or was she having seizures in spite of having enough phenobarbital in her blood? And if the parents weren't giving what we told them to give, was it because they hadn't understood or because they didn't want to? We just couldn't tell." The absence of good interpreters was only part of the communication problem. Neil felt that Nao Kao put up a "stone wall" and was sometimes deliberately deceitful. Peggy felt that Foua was "either very stupid or a loonybird" because her answers, even on those occasions when they were accurately translated, often didn't make sense. Neither doctor could tell how much of their inability to get through was caused by what they perceived as defects of intelligence or moral character, and how much was caused by cultural barriers. Neil recalled later, "It felt as if there

was this layer of Saran Wrap or something between us, and they were on one side of it and we were on the other side of it. And we were reaching and reaching and we could kind of get into their area, but we couldn't touch them. So we couldn't really accomplish what we were trying to do, which was to take care of Lia."

On June 28, 1983, MCMC asked the Merced County Health Department to send a nurse to the Lee home, accompanied by a Hmong interpreter, to try to improve the family's compliance with Lia's medication regimen. She was the first of a succession of public health nurses who were to visit the Lees over the next four years. One of the longest-lasting of them, Effie Bunch, told me, "The referrals were always the same. Febrile seizures, noncompliant mother, noncompliant mother, noncompliant mother, noncompliant mother. And the nurse's notes were always the same too. They always started out, 'The plan is. . . .' We all had a go at Lia and we all burned out." The visiting nurses tried putting stickers on the bottles, blue for the morning medications, red for the noon medications, yellow for the night medications. When Lia was taking elixirs, they tried drawing lines on the plastic syringes or medicine droppers to mark the correct doses. When she was taking pills, they tried posting charts on which they had drawn the appropriate pie-shaped fractions. They tried taping samples of each pill on calendars on which they had drawn suns and sunsets and moons. They tried putting the pills in plastic boxes with compartments for each day. Effie Bunch said, "I remember going over there and asking the mom to show me the meds. There they would be, a little stack of bottles in the kitchen next to the tomatoes and onions, sort of like a decoration in the corner. It wasn't hard to tell that the parents were really unhappy with the medical care. Because Lia was on such high doses, she had an appointment with Dr. Philp or Dr. Ernst almost every week and had a blood level drawn two or three days before and maybe another blood level two or three days afterwards, and there were so many changes that it was just totally mind-boggling. I don't think the mom and dad ever truly understood the connection between a seizure and what it did to the brain. And I don't know how else you get through to them that they have to give the meds. My general impression was that they really felt we were all an intrusion and that if they could just do what they thought best for their child, that child would be fine. They were courteous and they were obstinate. They told us what we wanted to hear. What we really knew about them wouldn't fill the bottom of a cup."

When Lia was between the ages of one and two, some of the notes the visiting nurses wrote on Merced County Health Department Encounter Forms were:

> Home visit made with interpreter. Parents state infant is doing the same. Were unaware of appt. @ Peds clinic for today. Were confused about proper dosage of medicine and which to give. . . . Several meds in refrigerator that are outdated included Amoxil and Ampicillin. Also one bottle of medication with illegible label. Dr. Ernst contacted concerning correct dosage of Phenobarb and Dilantin. Correct administration demonstrated. Outdated medication discarded.

> Mother states she went to MCMC as scheduled for blood test, but without interpreter was unable to explain reason for being there and could not locate the lab. Is willing to have another appt. rescheduled. States infant has not had any seizures. Have finished antibiotic. Are no longer giving Phenobarb because parents insist it causes diarrhea shortly after administration. Mother states she feels intimidated by MCMC complex but is willing to continue treatment there.

> Reluctant to give meds but has been giving Phenobarb & Tegretol but refuses to give Dilantin. State it changes child's "spirit" & makes face look different. . . . Each drug is in small compartment with appropriate day & time but medications gone from wrong day.

> Home visit again with interpreter who explained to the mother the importance of giving all 3 medications daily at correct times (mother has wall plaque which visually demonstrates type of med, amt & time to give medication) & possible results of return of seizures if meds not given. Mother seems to understand & states she'll continue to give Phenobarb & Tegretol but only 25 mg. of Dilantin AM & PM instead of 25 mg. at AM & 50 mg. PM. Agree to have continued care at Peds clinic.

> Home visit made with interpreter. Didn't have Medi-Cal card for child so didn't go to clinic. Doesn't know where Medi-Cal cards are. Mother has now decided to give 200 mg. Tegretol AM, 25 Dilantin in AM and 60 mg. Phenobarb at night. Mother seems very agitated.

Father out of house for rest of day—shopping. Mother still seems very unhappy with medical staff making decisions for daughter. Interpreter states mother *is* unhappy and Public Health nurse observed same by mothers tone of voice & body movements. Assured mother that child can be seen in Peds clinic Monday even without the Medi-Cal card.

Home visit by interpreter to discuss childs care with father. Interpreter states father also mistrusts medical system & wants another opinion but didn't state who or where.

Mother states they just returned from hospital that AM. . . . Diagnosis for hospitalization unknown to mother but antibiotic prescribed. Mother says she gave client Tegretol & Phenobarb this AM but that she feels there is no reason to give them as they don't do anything and that the Dilantin (previously prescribed) caused the child to be wild.

It did not take long for the public health nurses to answer Peggy Philp's question about whether the Lees were being noncompliant because they hadn't understood the instructions or because they didn't want to give the drugs. (Both.) Their faith in medicines had not been strengthened by two routine immunizations Lia had received against diphtheria, pertussis, and tetanus, to which, like many children, she had reacted with a fever and temporary discomfort. All of Lia's anti-convulsant drugs had far more serious and longer-lasting side effects. In some cases phenobarbital can cause hyperactivity—it may have been responsible for the riotous energy the nurses always noticed when Lia was hospitalized—and, in several recent studies, it has been associated with lowered I.Q. scores. Dilantin can cause hair to grow abnormally all over the body, and gum tissue to bleed and puff out over the teeth. Too much phenobarbital, Dilantin, or Tegretol can cause unsteadiness or unconsciousness. Although Foua and Nao Kao erroneously attributed Lia's "wildness" to the Dilantin instead of the phenobarbital, they were correct in perceiving that the medicines were far from innocuous. From that point, it was not an enormous leap to the conclusion they had reached by April 3, 1984, when a public health nurse noted, "Father had become more and more reluctant to give medications at all because he feels that the medicines are causing the seizures and also the fever."

The idea that the drugs prescribed to cure, or at least attempt to

treat, an illness are in fact *causing* it is not one that most doctors ever encounter. Doctors are used to hearing patients say that drugs make them feel bad, and indeed the unpleasant side effects of many medications are one of the main reasons that patients so often stop taking them. But most patients accept the doctor's explanation of why they got sick in the first place, and even if they resist the recommended treatment, they at least believe their doctor has prescribed it in good faith and that it is not designed to hurt them. Doctors who deal with the Hmong cannot take this attitude for granted. What's more, if they continue to press their patients to comply with a regimen that, from the Hmong vantage, is potentially harmful, they may find themselves, to their horror, running up against that stubborn strain in the Hmong character which for thousands of years has preferred death to surrender.

John Aleman, a family physician in Merced, once hospitalized a Hmong infant with severe jaundice. In order to determine whether therapy with special fluorescent lights would be sufficient or whether it would be necessary to perform a partial exchange transfusion, he had to take repeated blood samples to measure the baby's bilirubin level. After two or three samples, the parents said their baby might die if any more blood was removed. The doctor explained through an interpreter that the body is capable of manufacturing new blood, and he poured one cc of water into a teaspoon to demonstrate what an insignificant amount was being taken. To his amazement, his logical arguments only strengthened the parents' opposition. They said if the doctor drew any more blood against their will, they would both commit suicide. Fortunately, at this point Dr. Aleman asked his Hmong interpreter what he should do (a strategy not open to Lia's doctors during her early years, since no competent interpreter was available). The interpreter volunteered to call a Western-educated Hmong leader who was likely to understand the doctor's treatment plan; the leader called the head of the family's clan; the head of the clan called the father's father; the father's father called the father; the father talked to the mother; and, having thus received the request through a familiar and acceptable hierarchy, the parents were able to back down without loss of face. The baby had the blood tests and was successfully treated with phototherapy.

In 1987, Arnie Vang, a two-year-old Hmong boy who lived in

Fresno, was diagnosed at Valley Children's Hospital with testicular cancer. (Arnie's real name, the one conferred in his *hu plig* ceremony, was Tong, but his father preferred to call him Arnie because it sounded more American.) His parents, both teenagers who had attended American high schools and spoke and read English fairly well, consented, though reluctantly, to the surgical removal of the affected testis. After the surgery, Arnie's doctor, an Indian-born oncologist who had never had a Hmong patient before, explained that the next step was a course of chemotherapy. She handed the parents a piece of paper on which she had typed the names of the drugs he would receive and their possible side effects. Her predictions turned out to be accurate. Arnie, who had appeared perfectly healthy after his surgery, lost all his shiny black hair within three weeks after his first cycle of chemotherapy, and every time the drugs were administered, he vomited. Arnie's parents concluded that the chemotherapy was making him sick and refused to bring him in for further treatment. After giving the Vangs three days' warning, his doctor called Child Protective Services, the state agency that deals with child abuse, which dispatched two social workers and two police officers to their house.

Arnie's mother, Dia Xiong, explained to me later, "When they come, my husband isn't there. I say, Wait for my husband. But they say they can't wait. I say, Please that you go away. I hold my son. I hold him so tight. I say, Give my son back. Two police, they hold my hand behind my back. I can't move. I am scared. My two daughters are crying. The police hold my hand, they take my son away! I scream and cry. Then I take my husband's guns from the bedroom closet. They were two long guns. We bought them to shoot squirrels and deer, not to shoot people. I say I will kill myself and the little girls if they don't bring him back. I just yell, Please bring my son back to me. I say, Just bring! I want to hold my son!" A SWAT team was summoned, and for three hours the Vangs' immediate neighborhood was closed to traffic. Finally some police officers brought Arnie back from the hospital, and when Dia Xiong saw him, she dropped the guns and was driven, in handcuffs, to the psychiatric unit of a local hospital. She was released the next day, and no criminal charges were filed against her. Arnie's doctor administered one of the three remaining cycles of chemotherapy, but agreed, although it was against standard protocol, to forgo the last two. Arnie is still in remission today. His doctor was haunted for years by the thought that three lives were nearly lost in order to save one—"and for that one life," she told me, her voice shaking and her eyes filling with tears, "the cure wasn't even a hundred percent certain."

One night, while Lia Lee was in the emergency room at MCMC for the umpteenth time and a translator was present, Dan Murphy, who happened to be on call, brought up the subject of her anticonvulsant medications. Her mother informed him that she didn't think you should ever have to give a medicine forever. (It is likely that the only Western drugs Foua and Nao Kao had encountered in Asia were fast-acting antibiotics.) Dan recalled, "I remember that I was just watching them and they looked very resolute, like, you know, we are doing what we think is right. They weren't about to take any garbage. I felt they really cared for Lia, and they were doing the best, the absolute best they knew how as parents, to take care of the kid. That is what I felt about them. I don't remember having a feeling of anger, but I remember having a little bit of a feeling of awe at how differently we looked at the world. It was very foreign to me that they had the ability to stand firm in the face of expert opinion. Neil and Peggy are easily the best pediatricians in the county, yet Lia's parents didn't hesitate to say no to them or modify the drug dosage or do things however they saw fit. And the other thing that was different between them and me was that they seemed to accept things that to me were major catastrophes as part of the normal flow of life. For them, the crisis was the *treatment*, not the epilepsy. I felt a tremendous responsibility to stop the seizures and to make sure another one never happened again, and they felt more like these things happen, you know, not everything is in our control, and not everything is in your control."

Soon after this encounter, in the late afternoon of January 20, 1984, Dan Murphy was on call again when Lia came to the emergency room in the throes of a grand mal seizure. Among the notes he dictated were: "The patient is an 18-month-old Hmong child with a long history of seizures. The parents report that they had discontinued the medications about 3 months ago because the patient was doing so well." Dan did not have much time to reflect on this alarming news, because shortly after he started Lia's phenobarbital IV and admitted her to the hospital, he was called to assist at another emergency room

crisis in which the patient died, and, immediately thereafter, he was summoned to the obstetrical unit to deliver a baby. At 11:20 p.m., in the thirteenth hour of a thirty-three-hour shift, Dan was paged because Lia had started seizing again, this time violently. Since Lia had responded well to the phenobarbital, Dan had not summoned Neil Ernst or Peggy Philp to the hospital. He therefore had to deal on his own with the most severe episode of status epilepticus Lia had yet suffered. He administered two more massive doses of phenobarbital. "Sometimes you have to give so much medicine to stop the seizure that they stop breathing," said Dan. "That happened." Lia turned blue. First Dan gave her mouth-to-mouth resuscitation, and when she failed to resume breathing on her own, he decided that a breathing tube had to be placed down her trachea. "Lia was only the second child I had ever intubated under crash circumstances, and I didn't feel all that confident. You have this instrument that looks sort of like a flashlight, with a blade that snaps down, and you have to get the tongue out of the way, and the problem is that if you don't know exactly what you are doing, instead of putting the tube down the trachea you put it down the esophagus, and you start to ventilate but the patient is not getting any oxygen. So it's literally a do-or-die situation, either you get it in and they do okay or you don't and they might die. This time I saw what I needed to see and the tube went right in and it worked perfectly and I felt really good. I thought, well, I guess I am becoming a doctor."

Lia's parents were standing outside the ward while Dan intubated Lia. "By the time they came back in, she was unconscious and she had this tube taped to her mouth. I remember that they were very upset about that. I remember that the mother just had a very displeased look on her face." Because MCMC was not equipped with a respirator for babies, Dan decided that Lia, who was being given oxygen on a temporary basis through a manually operated bag, should be transferred by ambulance to their pediatric backup facility, Valley Children's Hospital in Fresno, sixty-five miles south of Merced. She regained consciousness there, and was able to breathe on her own after twenty-four hours on a respirator. Lia spent nine days in Fresno, spiking high temperatures from aspiration pneumonia and gastroenteritis, but did not seize again. On her History and Physical Examination form, her name is listed as Lai Lee; on her discharge summary, she is Lee Lei.

Through an English-speaking cousin who accompanied Foua and Nao Kao to Fresno, the admitting resident was told that Lia had been off medications for one week (rather than the three months recorded by Dan Murphy) because the prescription had run out and the family had not refilled it. The resident wrote, without irony, "I am not entirely sure if all the history is reliable."

Two months later, Peggy Philp noted in an Ambulatory Care Physician's Report that Lia, who was then twenty months old, had "no words (altho used to say sev. words)." In her diagnosis, she wrote "?Dev. delay"—a conclusion she had dreaded reaching for some time. It is not surprising that a child who had seized as frequently and severely as Lia was beginning to show the first signs of retardation, but Neil and Peggy found the situation particularly tragic because they considered it preventable. Looking into Lia's future, they foresaw a steady decrease in intellectual capacity unless the Lees started giving Lia her anticonvulsants regularly—and even that might not halt the decline, since the brain damage resulting from her erratic medication regimen had already made her seizure disorder far less tractable than it would have been if compliance had been perfect from the start. Neil and Peggy perceived Lia as being more retarded (though still only mildly so) than the visiting public health nurses did. Effie Bunch said, "The doctors only saw her when she was sick and never in her home environment. When we saw her, sometimes she was a windup toy because of the phenobarbital and sometimes she was post-seizure and looked like a little ball of dough in the corner, but sometimes she was just bright and cute and actively playing, happy, gay, climbing, crawling, on her mother's back, laughing and chattering and what have you." Testing Lia's intelligence was difficult because her hyperactivity made it hard for her to focus on assigned tasks, and both the doctors' instructions and Lia's verbal responses were always filtered through interpreters of dubious competence. When Neil and Peggy administered a Denver Developmental Screening Test at fourteen months, the results were normal, but at twenty-two months, although Lia passed "Plays ball with examiner," "Plays pat-a-cake," "Imitates speech sounds," and "Neat pincer grasp of raisin," she failed "Uses spoon, spilling little," "Washes and dries hands," "Points to 1 named body part," "3 words other than Mama, Dada," and "Tower of 8 cubes."

When Lia was two, a consulting neurologist recommended that she be started on Tegretol, continued on Dilantin, and gradually weaned off phenobarbital because it was contributing to, or even entirely causing, her hyperactivity. Unfortunately, the Lees had now decided that they liked phenobarbital, disliked Dilantin, and were ambivalent about Tegretol. A visiting nurse once found Lia dazed and staggering after receiving an overdose of phenobarbital (which, though it can raise some patients' energy levels when taken in normal doses, has the opposite effect when taken to excess). The next day, when Lia was brought to the pediatric clinic, the resident on duty—who happened to be Gary Thueson, the doctor who had delivered her—noted, "Apparently parents felt if phenobarb was good 2x is better so double dosed yesterday." On July 20, 1984, Neil Ernst wrote in a Pediatric Clinic Note (a copy of which he sent to the Health Department):

> The mother states that she will not give the Dilantin at home. In addition, she also states that she has increased the child's Phenobarbital to 60 mg. b.i.d. Finally the mother states that she ran out of Tegretol and the child has received no Tegretol in the last 4 days. The mother brought a large sack full of medication bottles and on closer examination by myself there were 3 half empty bottles of Tegretol. The mother stated that she was unaware that these bottles were Tegretol. In addition, the mother also was unable to identify the Dilantin bottle and gave that bottle to me and said that she did not want it at home.

On rereading this note many years later, Neil said he could still remember the rage he had felt when he wrote it. He and Peggy, who are both aware, and even proud, of their joint reputation for glacial unflappability, couldn't remember another case that had made them feel this way. "I remember wanting to shake the parents so that they would understand," said Peggy. A handful of times, Neil gave Foua a hug while Lia was seizing, but most of the time, while Lia was between the ages of eighteen months and three and a half years, he was too angry to feel much sympathy toward either of her parents. "The best thing I could have given Lia's mother was compassion, and I wasn't giving her any and I knew that I wasn't giving her any," he said. "There was just too much aggravation. It was like banging your head against a wall constantly and not making any headway. There was the

frustration of the nighttime calls and the length of time it took and the amount of energy and sorrow and lack of control. I mean, every time I saw Lia I would just, you know, it was like—ohhhhh, you would just get so frustrated! When she came to the emergency room in status there would be sort of like a very precipitous peak of anger, but it was quickly followed by the fear of having to take care of a horribly sick child who it was very difficult to put an IV in." Peggy added, "Some of the anger came from that. From our own fear."

It was hard to work so hard and not receive a single word of thanks—in fact, to have their efforts invariably greeted with resentment. Neil and Peggy never dwelled on the financial aspects of the case, since one of the reasons they chose to work in Merced was, in Neil's words, "to serve underserved people regardless of their form of payment." But it was an undeniable fact that Lia's family had never paid a penny for the hundreds of hours of care she had received—and yet failed utterly to appreciate the generosity of Medi-Cal and of Neil and Peggy's services, which, because of the low level of reimbursements, were, in effect, partially voluntary. (No other pediatricians practicing in Merced at that time were willing to accept Medi-Cal patients.) The Lees also never showed their doctors the kind of deference reflexively displayed by even their most uncooperative American patients. It was as if Neil and Peggy's four years of medical school, their three years of residency, their awards, their publications, their telephone consultations with neurologists, even the hours they spent in the Merced Public Library reading old *National Geographic* articles about the Hmong, all counted for nothing. The worst aspect of the case was that as conscientious physicians and dedicated parents, they found it agonizing to watch Lia, as it would have been for them to watch any child, fail to receive the treatment they believed might help her lead a normal life. And it seemed as if the situation would never end. However frustrated they were, they never considered abandoning the case. Unless Lia died, they could see themselves driving to the emergency room in the middle of the night until she was grown up and had graduated to the care of an internist, with whom they already felt an anticipatory bond of sympathy.

In June of 1984, Neil and Peggy found out that Foua was pregnant again. They were appalled. This baby would be number fifteen; eight had survived. Foua's age was unknown—it was listed on her maternity

registration form as fifty-eight, a number no one at MCMC seems to have questioned—but Neil and Peggy had assumed that she had already gone through menopause. "When we found out she was having another, we said, how could this happen?" Neil recalled. "This must have been the last egg that was possibly fertilizable, and it got fertilized. We were just dreading how this baby might turn out, that it might have Down syndrome and heart problems and that we were going to have to deal with *two* sick kids in this family. *Just* what we needed. Lia's mom refused to have an amnio. Not that she would have aborted anyway." Foua also vehemently refused a tubal ligation, a sterilizing procedure urged by a nurse who knew Lia and feared another Lee child might be born with epilepsy. She continued to breast-feed Lia throughout her pregnancy. On November 17, 1984, when Lia was two and a half, Pang Lee—a healthy, vigorous, completely normal baby girl—was born. After the birth, Foua breast-fed both Lia and Pang. She was exhausted and, according to a Child Welfare report, "overwhelmed."

On April 30, 1985, four days after Lia's eleventh hospitalization at MCMC, a visiting public health nurse found that the Lees were giving Lia a double dose of Tegretol pills, which they had stored in an old phenobarbital bottle. On May 1, the nurse noted that Lia's father "now refuses to give any Tegretol whatsoever." That same day, Neil noted that when Lia came to the pediatric clinic, "the family stated to me through the interpreter that they have stopped the Phenobarbital 5 days ago and the child apparently has received no Phenobarbital since hospital discharge. Mother stated that the combination of Tegretol and Phenobarbital was 'too strong' for the child and she decided to stop the medication."

Neil sent a copy of this note to the Health Department and to Child Protective Services. In it, he also wrote that

> because of poor parental compliance regarding the medication this case obviously would come under the realm of child abuse, specifically child neglect. . . . Unless there could be some form of compliance with the medication regimen and control of the child's seizure disorder, this child is at risk for status epilepticus which could result in irreversible brain damage and also possibly death. It is my opinion that this child should be placed in foster home placement so that compliance with medication could be assured.

The Superior Court of the State of California immediately acted on Neil's request, declaring Lia Lee to be a Dependent Child of the Juvenile Court who was to be removed from the custody of her parents.