

Giving life a chance

by Jutta Dinkermann

Wir durften nicht aufgeben!

by Karl-Eugen Siegel
Gütersloher Verlagshaus,
Gütersloh, Germany, 1993
190 pages, DM 19.80

At the end of 1992 the "Erlangen Baby" case sparked a heated debate on the question of whether the bodily functions of a brain-dead pregnant woman should be sustained, in order to keep her unborn baby alive. A year earlier, Gabi Siegel's husband decided to go ahead, in the certainty of a deep solidarity with his wife. His gripping diary, *We Were Not Allowed to Give Up*, depicts the course of the pregnancy and birth of their son Maximilian Matthias, who has since become a healthy, frolicking two-year-old.

The author makes it clear that he did not wish to write a book about his experiences. However, shortly after the first birthday of his son, he learned about the case of the Erlangen baby. Shocked and indignant that the majority of the population, the media, politicians, theologians, and doctors were calling for the immediate cutoff of life support systems from the "Erlangen mother," he decided to stand by the family's wishes by publishing his own experience (see accompanying article for the story of the Erlangen baby).

"The media had their sensation," he wrote, "of the alleged first case of a brain-dead pregnant woman in Germany. The headlines announced that here, a 'corpse was being used,' or even talked of a 'child of the dead,' or 'an orphan from birth,' coming into the world. Women's rights advocates and feminist politicians got into high dudgeon over the 'degradation' of the dead mother into an 'incubation machine.' I do not believe that I must explain what feelings I had in reading such coverage. Nor could I imagine that I would have stood up to, in the situation of that time, such unserious reportage about our case. All the more did I want to help by depicting our experiences and above all, by sending a signal."

On July 4, 1991, Gabi Siegel, then in her 16th week of pregnancy, was found unconscious on the street by a doctor passing by. The origins of her breakdown were not clear; the doctors told the author that his wife had suffered a massive lack of oxygen and that permanent brain damage was certain. They did not want to give him any hope for the infant and

made fighting to save the life of the mother their first priority. Here the husband intervened for the first time with the request to do everything possible for the mother *and* for the child.

Alone with his unconscious wife, he reported to her on his thoughts in his desperation. He even read from the book *On Family Life*, which deals with the sweeping and serious moral tasks of education, and states that through the education of one's own children, the moral fitness and maturity of people first become evident. They had talked together about this only days before Gabi's collapse. "We must now prove that we possess this moral steadfastness, and therefore are also qualified to raise a child," he said. "Even with what has happened, we three can overcome it."

The next day the mother's cerebral condition continued to be as bad as ever, and no information could be obtained as to which part of the brain was most severely affected. Because of her pregnancy, certain tests could not be carried out, which might have shed more light on this. The chief surgeon stated that other parts of Gabi's cerebral cortex could not take over the tasks of the damaged regions, because the shortage of oxygen had affected the entire brain. Before a clear determination could be made, days or even weeks would have to pass. The husband insisted unconditionally, too, on saving the unborn child, even though he was aware of the danger of physical or mental damage to the child. He knew that he was united with his wife, since they had shared their thoughts on various occasions.

In the ensuing days he was concerned not just for his wife, but also about his wife's aunt, who was hospitalized for a stroke. Mr. Siegel felt that the way the nurses were dealing with her was not in keeping with human dignity. "I must involuntarily think about Gabi; I believe it depends on the environment, whether a broken-down, nearly extinguished life is still worth living or not," he wrote in the evening in his diary. "What can a chained person do for himself? He needs help from someone who can break his chains." He got the idea of founding a nursing home, "in order to prove that our society is capable of breaking through the limits of capitalism and the market economy, and acting in a social and human way."

Gabi's father was shocked when he saw his daughter, and thought it would be better for her to die, since her condition had not improved and she would remain always under care. The husband confided to his diary: "I understand him, but I cannot accept it. Not out of selfish motives, but because even the life of a person needing constant care can be shaped as worthy of living. Besides, through this death undeniably a second life would be snuffed out, that of our child."

On the ninth day, the doctor confronted him with the reality that, because of the child, potentially important medications could not be administered to the mother. Therefore he had to think everything over again. Mr. Siegel was racked by doubts, but he stuck to his decision not to agree to anything that would induce abortion, as long as it was questionable

whether the therapy would really help bring better results for his wife.

'She and I are of one mind'

On the eleventh day, things grew dramatically worse. Gabi's pupils no longer reacted at all. The doctor told him, that the onset of brain death might possibly be at hand. When the encephalogram reached zero (which occurred on the 14th day), her brain would be irreversibly dead.

The diary of the following day testifies to his thinking in the face of this desperate situation: "You sit on the bed, caressing a body which belongs to your wife, speak with her, not knowing what her state is. . . . I am so happy to know that she and I are of one mind, that my thoughts are also Gabi's and hers are mine. This is the way also with decisions which come up and must be made. I am sure that she does not envy me these decisions."

After the neurologist informed him that he thought there was no longer a chance for his wife, but that the placenta was working quite autonomously, Mr. Siegel carried on a discussion that same day in an anthroposophist-oriented clinic, where his wife might possibly be hospitalized. The young doctor with whom he spoke already had considerable experience, and knew that many medical situations are unforeseeable. He appreciated Mr. Siegel's commitment and that they had also decided to take the risk of a handicapped child.

In the women's clinic of another hospital, he had a very different, probably more typical experience with the doctor in charge. This one designated Gabi as "a human incubator," and was for ending her life. Mr. Siegel was incensed and told him of his commitment. When he was then again invited at least to have an amniocentesis performed, in order to see whether the child had birth defects, he replied to the doctor that he neither wanted nor needed this, because "even a handicapped child can represent an enrichment of life. . . . Why do such children have no right to life? Because of society, which has not yet learned to live with handicapped people? Because it is alleged that such a life is not worthy of living?" "I have already had quite different experiences," he informed the nonplussed surgeon. The doctor was so impressed after this one-hour conversation, that he wished him good luck for the child with all his heart, and discarded the "human incubator" theory he had earlier expressed.

On the 36th day after her hospitalization, Gabi Siegel was taken to the anthroposophical clinic. Her husband, throughout this whole time, was on leave from his work and spent most of his time next to his "two." He read aloud, talked to them, had music played, and maintained bodily contact. The medical regime included physical, musical, and eurhythmic therapy. The care staff were involved, but had great difficulty understanding Gabi Siegel's situation. This changed only when they had the opportunity to speak at length with her husband. "Then you know how much he cares for her and the child," one nurse said.

'Proud of their mothers'

On the 86th day, she went into labor, and the child was delivered by caesarian section. The father was allowed to be present at the delivery and depicted the atmosphere in the operating room with the words: "They rejoiced with me that everything up to now had gone so well and without friction. We all really were happy. There were others who turned up, because it had been talked about all over the clinic. It cannot be described, it was for everyone who came a source of quiet joy. I think they came also to see the miracle. Our Siegel child, because at this point I had not yet picked a name for our son, weighed at birth 1.65 kg and was 38 cm long."

That evening, the first resuscitation of his wife was

The 'Erlangen baby' debate

A little over a year ago, a huge debate exploded in Germany over the so-called Erlangen baby. In the Surgery Department at the Erlangen University Clinic in Bavaria, an 18-year-old woman who was four months pregnant was being kept alive on life support systems until such time as the infant could be safely delivered by caesarian section. The apparatus involved heart and lung machines and intravenous feeding and parenteral feeding, while the progress of the child was monitored day and night by sonograms. The parents of the young woman had consented to these measures, and the clinic staff were fully engaged emotionally in the fate of the young woman and her unborn child.

The print media got wind of the extraordinary situation and printed numerous "pro" and "contra" opinions, which set off a lively echo in the letters columns. On Nov. 11, 1992 the German newspaper *Neue Solidarität* published an analysis of the controversy by Dr. George Goetz, MD, of Augsburg, the chairman of "European Doctors' Action."

Dr. Goetz quoted from the tangle of opinions expressed in readers' letters, much of which expressed rage at the medical profession: "What has happened, is undignified and irresponsible—this experiment sends chills up and down the spine—the woman is no incubating machine—the mother is degraded into a food supply—the child in a soulless incubator—a living corpse is sacrificed on the altar of modern technological medicine—a dignified death is more important than a pregnancy—you doctors are perverse desecrators of corpses—a scarcely tolerable perversion of humanity." He also cited newspaper reports which spoke not just of a "brain-dead pregnant

carried out after she suffered a circulatory collapse. The doctor asked him if he wanted to revive her again in the future. He would do it again, but huge problems might arise. On the next day, his wife grew worse and worse. Without the opportunity arising to revive her again, Gabi Siegel died the next night.

Their newborn son, Maximilian Matthias, now remained in intensive care, but on Dec. 13 he was released and went home with his father. "Max is a very outgoing, merry, and very playful child," he says in the final chapter. "We celebrated his first birthday with our relatives, with friends, the doctors, the nursing personnel and the therapists who had cared for us. Binding friendships came from this. . . . They all gave

their best and are happy with us that Maximilian Matthias is developing so successfully."

The book ends with the words: "Meanwhile Max has become 17 months old and understandably, like all children of his age, a true scamp. . . . But he knows our story so far only from his own experience and only from his view. This, too, will change some day, and he must perhaps have it out with others with polemical statements and commentaries about his unusual birth. . . . Perhaps this book will contribute a piece so that he and other children will be proud of their mothers, who often remain alive weeks or months and linger in a transitional condition, until their child has a real chance of surviving."

woman," but of a "corpse" and a "dead woman."

What is 'brain death'?

Dr. Goetz explained that when so-called "brain death" occurs, a special protocol is drawn up which establishes the criteria of brain death—unconsciousness (coma), lack of spontaneous breathing, pupil immobility, the lack of various reflexes, and especially, the absence of reactions to pain stimuli. A brain death protocol is required by law in Germany (as elsewhere) in order for organs to be donated. "The full, irreversible, permanent loss of functioning of the entire brain is thus the criterion for brain death," he wrote. This is "not to be confused with the coroner's certificate, which concerns a dead person, and involves different criteria, namely, lividity, cooling of the body, rigor mortis, and decomposition."

The Bavarian state assembly even got into the fray at the behest of the Green Party. A feminist member of the ruling Christian Democratic Union, Angelika Pfeiffer, expressed deep shock about the artificial maintenance of the pregnancy of a brain-dead woman, but as Dr. Goetz pointed out, "I too was shocked," since Pfeiffer's name figures on the list of 32 CDU dissidents who voted against their party for a "right to die" (euthanasia) bill in the federal parliament.

"Among the basic principles of the practice of medicine stands the lofty task of protecting life, and when it is in danger, of saving life, and preserving life until natural death, in conformity to human dignity. Today, a four-month-old baby has been proven to be alive (under ultrasound control) in the womb of the mother thanks to the intensive efforts of a medical team under the responsible direction of surgery professor Dr. Johannes Scheele."

Dr. Goetz also pointed to a joint declaration of the Evangelical and Catholic Churches of Germany in support of organ transplantation, which depends on a voluntary declaration by the donor while living. "The churches have

valued organ donation as a sign of charity and solidarity with sick and disabled people. Pope John Paul II, at the first International Congress of the Society for Organ Transplants, spoke of love, self-sharing, solidarity, and absolute respect for the dignity of man as the only fitting framework for organ transplants. Since 1976 more than 20,000 kidney transplants have been carried out in Germany alone."

Dr. Goetz then quoted a letter to the *Augsburger Allgemeine Zeitung* of Oct. 24, 1992, which "speaks from the heart of many women." The letter read, "Can no one then understand the parents' decision? Their child is dying and the only thing that remains is the unborn, unharmed life in their daughter's womb. They can give to their future grandchild what is forever gone and no longer possible with their daughter. I myself am pregnant and would also wish, if something happens to me, that my child can and may live on as part of me."

"In the Erlangen case it is not a question of artificial measures sustaining one person, but rather two persons—the brain-dead mother and a living human child of more than four months," Dr. Goetz wrote. "To send the brain-dead mother to her definitive death by unplugging the heart and lung machines, would definitively mean that her baby, which was healthy and wanted to see the light of day, would die. One cannot speak of any wish for death on the part of the unborn child. The result of a passive euthanasia in this case would mean two corpses. According to the German Constitution, Art. 2.1, an unborn child, whether healthy or sick, has 'the right to life and bodily integrity.'"

"How many people thank organ transplants for a happy life? The Erlangen baby may also rejoice, if in the course of the coming weeks, the constant readiness of the doctors and their medical collaborators succeed in prolonging life and thus bringing the unborn child to an optimal situation," Dr. Goetz concluded.