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MR. CHAIRMAN, my name is C. Everett Koop. I am a physician and the Surgeon General of the United States Public Health Service. I am here today as the Surgeon General to speak for the Department of Health and Human Services. However, for the subject that is before the Committee this morning, I will also draw upon my personal experiences of 35 years as a pediatric surgeon. When I began that career there were only a half dozen people in the world who specialized in surgical procedures for infants and young children. Pediatric surgery has since become an important life-saving specialty in medicine and I am very proud to have been part of that history and development. When I came to Washington last year I had been practicing the specialty of pediatric surgery longer than anyone in North America.

Before I continue, Mr. Chairman, may I introduce to the Committee my colleague, Ms. Betty Lou Dotson, who is Director of the Office of Civil Rights of the Department of Health and Human Services. The two of us look forward to discussing with you and this Committee some of the many issues surrounding the issue of care for the newborn child with handicaps or operable defects.

The subject of this hearing is taken from the title of a piece of proposed legislation called "On Withholding Treatment from Infants with Handicaps and Other Operable Defects." I hope that as we proceed this morning, Mr. Chairman, we may be able to move away from the negative viewpoint of that title and pay more attention to the <u>provision</u> of treatment for such infants.

I am sure you will agree that our government — regardless of the branch or which political party may be dominant at the time — is primarily concerned with the provision of health and medical care, not about withholding it. Indeed, that point of view was emphasized by President Reagan last spring in an April 30 memorandum in which the President instructed both the AttorneyGeneral and the Secretary of Health and Human Services to exercise their authorities to enforce Federal laws that prohibit discrimination against the handicapped. President Reagan took special note of Section 504 of the Rehabilitation Act of 1973, which (and I quote from the President's memorandum) "forbids recipients of Federal funds from withholding from handicapped citizens, simply because they are handicapped, any benefit or service that would ordinarily be provided to persons without handicaps." The President noted that the law specifically applies to "hospitals and other providers of health services receiving Federal assistance."

The closing paragraph of the President's memorandum sums up the policy of this Administration regarding medical care for handicapped infants.

> "Our Nation's commitment to equal protection of the law will have little meaning, if we deny such protection to those who have not been blessed with the same physical or mental gifts we too often take for granted. I support Federal laws prohibiting discrimination against the handicapped and remain determined that such laws will be vigorously enforced."

As a follow-up to the President's instruction, Secretary Richard S. Schweiker asked Ms. Dotson to issue a notice to health care providers which are reimbursed under Medicaid and Medicare. The Secretary said, "In providing this notice, we are reaffirming the strong commitment of the American people and their laws to the protection of human life." With your permission, Mr. Chairman, I would like to submit for the record both the Department's "Notice to Health Care Providers," dated May 18, and the Department's press release of the same date. Ms. Dotson will then discuss the Notice to Providers in her remarks.

The President's instructions and the Department's Notice to Health Care Providers were a result of a recently widely publicized occurrence in which a handicapped newborn infant, called "Infant Doe," was allowed to die.

Infant Doe was born with Down Syndrome, a form of mental retardation that is genetically transmitted. We know that Infant Doe also suffered an esophageal atresia, a malformation of the esophagus which prevents the taking of nourishment but which may be corrected with surgery. Surgery was not performed to correct the atresia; Infant Doe was not fed, either orally or by intravenous method and, seven (7) days after birth the child died.

The basic principle in this case is that the child was allowed to die because someone else made the judgement that the child's life was not worth living. Mr. Chairman, I can assure you that there is no way to assess or to estimate the I.Q. or the potential of a Down Syndrome child at the time of that child's birth. But whatever the degree of retardation may be, this handicap is never a justification for witholding treatment.

In all cases of esophgeal atresia, corrective surgery is indicated and is nearly always successful. In my own experience, I did not loose a full term baby in the last eight years that I was a surgeon and my survival rate for premature babies was 88%. I do not mean to minimize the difficulty for the surgeon, the anxiety for the parents, or the discomfort of the patient. These are all familiar to me, as I was among the first to perform such an operation nearly 35 years ago and since then my colleagues and I have done some 475 procedures. Each case was special. But after recovery, these babies were all able to take nourishment by mouth.

Mr. Chairman, just as an aside, let me say that one of the benefits of being a 65-year-old pediatric surgeon is that now and then I meet some tall, good-looking man or woman, full of life and health, whom I had first met as a newborn lying on my operating table, struggling with an esophgeal atresia or another condition, which was successfully corrected.

Such procedures are no longer unusual. And often it seems as though every day medicine adds another new life-saving procedure to an already impressive list of victories. More and more therapeutic options are opening up, giving physicians greater opportunities, in the words of the Hippocratic Oath, "to help the sick according to my ability and judgment, but never with a view to injury and wrongdoing."

In other words, Mr. Chairman, to return to the issue before us this morning, the professional medical question posed by the birth of a disabled infant is "How can we treat this baby, save its life and improve its potential quality of life?" The President's memorandum and our Department's notice to providers, ought to be seen in this context, as indicating the government's support for the provision of — <u>not</u> the withholding of — treatment for disabled infants. In this respect, an enlightened government becomes the natural ally of enlightened medical practice.

In my experience, this type of event has two aspects to it, and each one is important. First, there is the nature of the medical problem presented by the infant itself. Second, there is the role of the family of the infant, the people who are responsible for the infant appearing in the first place.

I indicated that medical and scientific advances constantly provide new ways to save lives and improve the quality of life for the newborn. But medicine may <u>never</u> have all the solutions to all the problems that occur at birth. I personally foresee no medical solution to a cephalodymus or an ananocephalic child. The first is a one-headed twin; the second, a child with virtually no functioning brain at all. In these casesn the prognosis is an early and merciful death by natural causes. There are no so-called "heroic measures" possible and intervention would merely prolong the patient's process of dying.

Some of Nature's errors are extraordinary and frightening...but Nature also has the kindness to take them away. For such infants, neither medicine nor law can be of any help. And neither medicine or law should prolong these infants process of dying. I would presume that these unfortunate exceptions are not the center of this Committee's interest.

In most instances, however, the course of treatment is quite clear. The vast majority of disabled infants are within the realm of treatment. Moreover, Mr. Chairman, I believe there is one "bottom line" in all these cases and it is that you feed the patient - either orally or intravenously. Indeed, in the case of Infant Doe, the fact that nourishment was witheld probably did more than any other single fact to shock the medical profession and the general public. Finally, Mr. Chairman, we should not let anyone's emphasis on the most difficult cases distract our attention from the basic principle that we must not discriminate against handicapped infants.

This point was made on May 18 by Assistant Secretary Dr. Robert Rubin in the course of his appearance on the evening television show, "The MacNeil-Lehrer Report." Speaking for the Administration, Dr. Rubin said,

> "We're not talking about prolonging a life that inevitably is going to die. What we're talking about here is discriminating against children who, if it weren't for the fact that they were handicapped, would be given appropriate medical treatment."

Mr. Chairman, I want to focus now on another question and draw from my personal experience as a physician. Once a handicapped child is being cared for within the realm of medicine, what ought we reasonably to expect from physicians?

let me suggest several principles that some physicians have found useful when they confront the kinds of situations we are discussing:

First, the physician must know a great deal about the infant's disease process or disabling condition. As science and medicine continue to evolve, this is an ever-growing responsibility and requires that the physicians must have great knowledge about and experience with the lesion in question.

Second, the physician has to know as much as possible about the patient.

Third, based on the first two, the physician has to draw some very important conclusions about how that process or condition affects this particular patient.

Fourth, physicians should be extremely cautious in making any guesses as to the "quality of life" the patient will ultimately enjoy. We frequently have absolutely no way of predicting how happy or smart or active a person may be at some point down the road in his or her life. The task for the physician is to do whatever possible so that the patient can enjoy to the fullest whatever he or she ultimately determines is "quality."

Mr. Chairman, I said that there are two aspects of these cases that bear close study. The first aspect I have just discussed and its focus is directly upon the infant and the infant's medical condition. The other aspect concerns the type of support the infant's family is given by the physician, the hospital and the community.

I would like to suggest certain principles which, if followed, will enable those who care for a handicapped child to work better with the family to achieve the greatest possible benefits for the child. Having followed these principles, I can also tell you that I have never had a patient or a parent tell me that they wished I had not saved their life or that of their child. And I can alos tell you that many of these children suffered conditions that I, personally, would have found difficult to bear.

First, the physician must sit down with the family and thoroughly go through the nature of the infant's condition, what the medical experience with such a condition has been so far, what kinds of things can be done immediately, and what the options may be later on.

Second, the physician must be familiar with and understand the natural responses of parents to the disabled newborn...their feelings of sadness, guilt, anger, even of shame. The parents will be concerned about the judgments of their neighbors and friends. Therefore, the physician represents not only medical care -- but the outside world as well.

Third, the physician must demonstrate that the parents are needed as partners in the processes of medical care and that, for a disabled infant just as for a "normal" child, there is just no substitute for loving, caring parents. Gradually, as the network of support grows, the parents will become more centrally involved and more competent to care for their child and for themselves, too.

Fourth, a physician should try to get the child into the hands of the family just as soon as possible. Staring through a pane of thick glass at a little baby in a covered isolette over in the corner is just not my idea of how to bring parents and any new child together. In my own experience, I suggest that the parents visit the child as soon as possible. Even though the baby may be bandaged, intubated, monitored, and fed with a hyperalimentation line, the parents can and should touch the child -- if possible, hold it and cuddle it.

Fifth, physicians and hospitals must take a positive, active role in getting the parents and the child linked up with available social and medical support groups in the community. Continuity of care and total care is important for all patients -- it is critical for infants with a disability. And above all the responsible physician must have the mind set and commitment to assure the family that he or she will be an advocate for their child and for the parents.

Finally, Mr. Chairman, I want to commend you for holding this hearing and for focusing congressional attention on this important and complex issue. I believe that the people of our country have demonstrated recently just how concerned they are about protecting and caring for newborn babies, regardless of whether they are "perfect", whatever that means.

In conclusion, Mr. Chairman, permit me to drift back to science and medicine for a moment. If the decisions in this area that we face today seem complex, then the future holds even more complexity, and for one important reason — it also holds more hope. What is extraordinary in medicine today will be ordinary tomorrow. What was extraordinary in medicine yesterday is ordinary today. And this is perhaps true in no field more than it is in neonatology.

During the past decade we have made progress in neonatology, in intensive care for newborns and in pediatric surgery that enables us to treat successfully many conditions that were not treatable only a few years ago. The mechanical ventilator and various other automatic monitors and devices enable us to provide the precision care required by very premature and very sick babies. Advances in pediatric surgery allow us to restore and repair organs and limbs whose malfunctions and malformations previously caused death, deformity and permanent disability.

We all must work together to enable those who care for the less-than-perfect newborn to continue their remarkable work. The most compelling opportunity is for our government and our nation's leaders -- in all fields and at all levels -- to reaffirm our national commitment to providing compassionate and high high quality medical care for all our Nation's children. The President and Secretary Schweiker have done that and as the Surgeon General I am pleased to do so again today.

Thank you, Mr. Chairman. Ms. Dotson has a short statement describing the activities of the Office of Civil Rights and then she and I will be happy to answer questions.