Trisomy 13 — A Dilemma

For a couple desirous of having a baby, to be told that the unborn child is a severely handicapped baby with a genetic disorder, trisomy 13, is a terrible blow and vastly disappointing. If born live, such an affected child will rarely live beyond 3 or 4 months.

The child with trisomy 13 has a small head with malformed ears, and is frequently deaf. A cleft palate and harelip, as well as malformed thumbs together with extra digits, are frequently found with this disorder. Such individuals, also, have severe mental retardation along with the physical abnormalities (see, for example, Daniel L. Hartl, Human Genetics, New York: Harper, Row Co., 1983).

Genetic Basis

The root of the problem is a chromosomal abnormality. Of the 23 pairs of chromosomes, the pair, which by standardized designation is known as number 13, is characterized by the presence of one extra chromosome, hence, trisomy 13 (that is, three number 13 chromosomes). The presence in every body cell of the extra chromosomal material results in the various malformations and deficiencies found in this disorder.

The condition is not predictable and is not a familial trait; it occurs sporadically in the general population at the rate of about 1 out of every five thousand live births. There is no known cause for the trisomy condition, but it represents a defect which occurs during cell division. No external environmental factor has been specifically implicated in the occurrence of trisomy 13.

A Couple’s Dilemma

This defect may be discovered before birth through the use of amniocentesis. Because of some previous experience, such as a miscarriage, a couple may wish to have a prenatal diagnosis made in order to feel more secure about the pregnancy or in order to be better prepared for the birth of a child with some handicap. Unfortunately, the attitude which seems prevalent today in some quarters is that if the unborn child has some severe abnormality, it is best for all that the child be aborted. For a couple who respects human life, this course of action is unacceptable.

The problem becomes particularly poignant when the couple has not as yet been successful in having a live child born and is despairing increasingly with each spontaneous abortion. With each pregnancy the wife and husband fear the prospect of either another miscarriage or having a severely handicapped child born with a life expectancy of only 3 or 4 months.

Moral Stance and Witness

With the various pressures — emotional, social and economic — on the couple, it requires a special courage not to yield to the temptation to abort the child. That stance is based on the rightful conviction that an innocent human life is sacred and inviolate, no matter what might be the age, health or condition of the individual. (Innocent, here, means not guilty of a crime worthy of death — if such there be.)

The Church has, in many ways, insisted on that truth and the

(continued on page 2)
heinousness of the crime which deliberately and knowingly terminates such a life. To emphasize the gravity of the situation, the Church has attached an excommunication to anyone who freely and knowingly procures an abortion. In modern times the Church hesitates to employ such strong sanctions, but it does so here because of the frequency with which this crime is committed — some 1,500,000 abortions a year in the U.S. alone, for example.

More important than the rightful fear of incurring an excommunication, is the positive respect for life and the strong visible support which family and friends can give. In these times, when human life appears to be a throw away item, it becomes all the more urgent for persons who believe in the sacredness of human life to speak forth strongly in support of life. Couples who are facing the dilemma of trisomy 13 can provide convincing testimony to their belief in life by steadfastly refusing to abort their unborn and socially unwanted baby.

Course of Action

Some women faced with the forthcoming birth of such a handicapped baby might be fearful of seeing their baby after birth, preferring to have the infant adopted without having had any contact. However, the advice of genetic counselors (some, at least) is that it is better for the mother to see and hold the child, even if briefly, before relinquishing him for adoption. There is the concern that without that experience, the mother will always wonder how that child really looked. Of course, it may happen that the mother may decide to keep that child.

With advance warning that a handicapped child (e.g., one with trisomy 13) is awaiting birth, it is of great importance that the family rally in support of the woman. The husband, siblings, parents and other relatives need to strengthen her decision not to abort the baby. The pastor and others need to reassure her that this child is not the result of something she, or her husband, did, it is not a punishment for sin.

If the couple decides to keep the infant, they will need guidance, support and help. A genetic counselor, for example, can provide guidance to the resources available in the local community to deal with the day-to-day problems associated with raising a severely disadvantaged infant.

While viewed from a purely human perspective, the birth of a child with a trisomy 13 disorder is a tragedy, a Christian sees it also as the opportunity to extend compassionate care to one of the most needy of Christ’s brothers and sisters.

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Assisting The Infertile Couple

Part Three: Possible Alternatives to Artificial Insemination and In Vitro Fertilization

The previous articles in this series dealt with ethical means of collecting semen for diagnosing causes of male infertility (Part One) and clearly licit therapy for many infertility problems (Part Two). Here in Part Three we will explore additional ways which may assist, in what (it can be argued) is an ethical way, those couples with infertility related to unexplained causes or problems that are not successfully treated by licit therapies we previously discussed. The therapies proposed here, then, are put forward for further consideration and discussion, rather than as recommendations for any practical therapeutic implementation at this time. This is especially true of a new technique, gamete intrafallopian transfer (GIFT), which has some complex and subtle moral aspects to it. Other techniques which we will discuss here have been proposed previously as licit by some authors, while others have rejected them.

Moral and Medical Distinctions: Artificial Insemination, In Vitro Fertilization and Aids to the Natural Act

Artificial insemination by the husband (AIH) or by a donor (AID) is a technique proposed for difficult infertility problems, but as generally practiced, is rejected by the Church. In vitro fertilization (IVF) has been rejected by those Bishops’ Conferences which have explicitly considered it. But apart from a parenthetical remark by Pius XII (1956), Rome has been silent, apparently awaiting more information and allowing time for mature reflection before making a definitive pronouncement. The serious reasons for these rejections have been previously explored in numerous issues of Ethics and Medics (See, for example, Ethics and Medics, September 1982, December 1982, October 1984, and November 1984).

The Church’s objections to these techniques come from understanding the procreative act as also a physically embodied love act, one which flows obviously from the heterosexual nature of the human race. Children are to be products of this complete, natural expression of love between married partners. That love act, including all its basic physiological structure, is normative for any and all human sexual activity. Other related objections include social concerns, objection to the loss of fertilized zygotes in IVF and embryo transfer (ET), the adulterous aspect of AID, and the method often used to obtain semen (masturbation).

While magisterial teaching and theological explorations make it clear that AIH, AIS, and IVF are beneath human dignity and, therefore, not to be used by practicing Catholics, nevertheless,