Prolife Reporter
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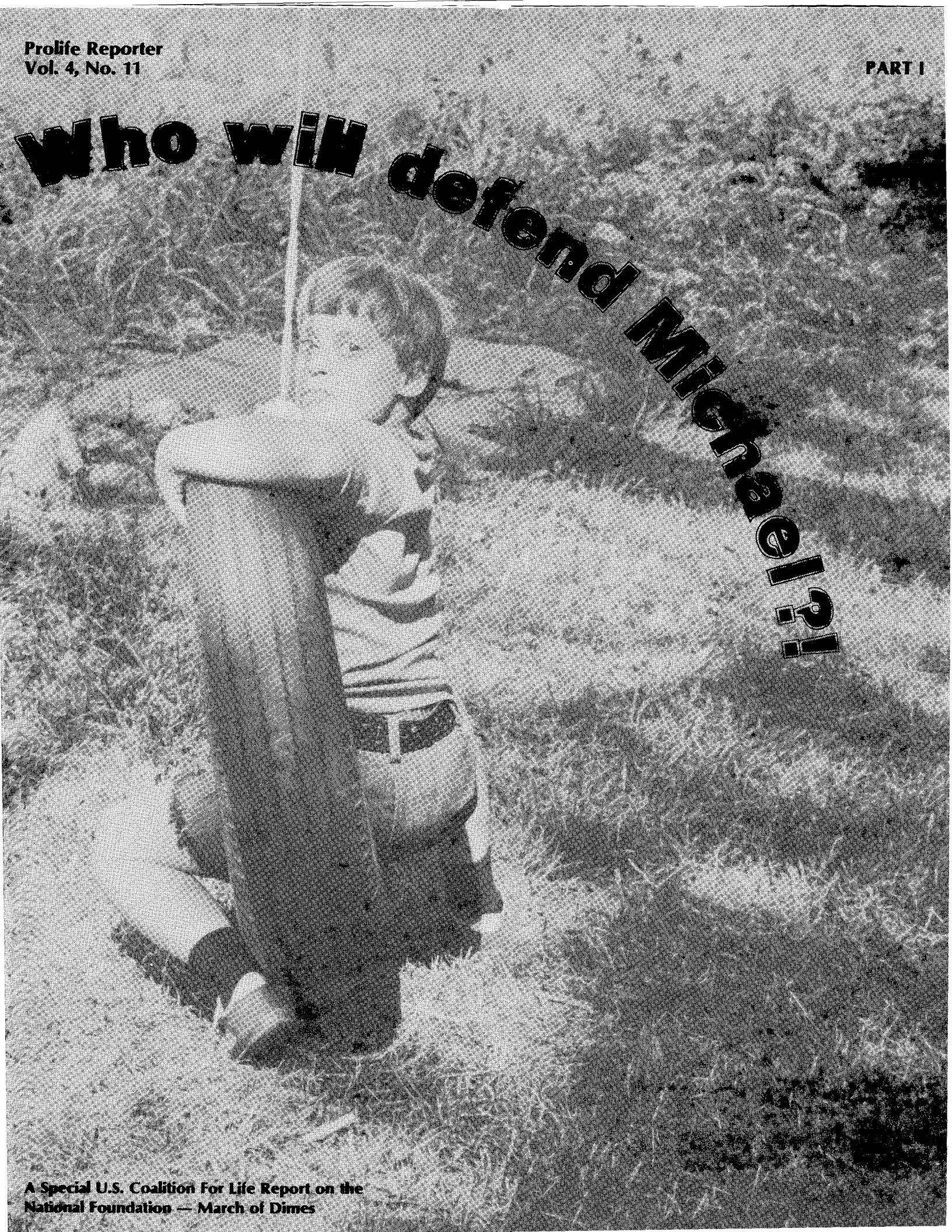
PART I

Who will defend Michael?



A Special U.S. Coalition For Life Report on the National Foundation — March of Dimes

Seven-year old Michael Policastro is the son of Mr. and Mrs. Thomas Policastro of Murrysville, Pennsylvania. Michael was born on February 15, 1969 with Down's Syndrome.

Michael is truly an exceptional child with an exceptional family and an exceptional educational background.

Thomas and Patricia Policastro are officers of the U.S. Coalition for Life and outspoken advocates in the defense of the retarded and handicapped child and his family.

Michael's brother John Philippe and sister Mary Alice are mini-reflections of their parents love and concern for all children — born and unborn — and most especially for little Michael.

Michael received his pre-school education and training from St. Peter's Development Center in Monroeville and is currently enrolled at the Clelian Heights School for Exceptional Children in Greensburg.

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U.S. COALITION FOR LIFE

SPECIAL REPORT ON THE NATIONAL FOUNDATION MARCH OF DIMES

PREFACE

A professional fund raiser once observed enviously that **BASIL O'CONNOR** — Franklin D. Roosevelt's law partner and the first president of the **National Foundation for Infantile Paralysis** which was incorporated in 1938 to lead, direct and unify the fight against polio — "had an unbeatable combination. *He had the kid in the wheelchair, the heart-throb without which you can't raise a sou in this country. He had the sponsorship of Franklin D. Roosevelt. He had the disease that everyone was afraid of.*"[1]

One might also add the National Foundation had a snappy "memory-arresting" slogan coined by the Late Eddie Cantor at the NF strategy meeting in Hollywood. "We could ask the people to send their dimes directly to the president at the White House," said Cantor. "Think what a thrill the people would get . . . and we could call it the **March of Dimes!**[2]

And the dimes added up quickly — from $1.8 million in 1938 to almost $67 million in 1955. Amidst a virtual financial wasteland for medical researchers, O'Connor's organization would provide a lucrative financial oasis for the handful of scientists selected by the NF's influential Advisory Committees. In return the Foundation accepted the mantle of scientific respectibility and prestige, essential ingredients for a successful fund raising campaign and effective alliance between the contributing public, volunteers, and the medical and scientific community.

The Salk Controversy

On April 12, 1955 — the tenth anniversary of Roosevelt's death — and the seventeenth anniversary of the founding of the National Foundation — America greeted with traditional fanfare, the news that the Salk vaccine — developed with funds wholly supplied by the March of Dimes — was pronounced **safe, potent** and **effective** against the child-crippler — **POLIO.**

Truly a major chapter in the history of medicine in America had been written, yet only a handful of medical professionals and laymen would appreciate its significance and impact on the future of medicine in the United States. One of those rare individuals was Dr. Herbert Ratner, who was Director of Public Health of Oak Park, Illinois and a vocal critic of the Salk vaccine.

The following excerpts were taken from an interview conducted by Donald McDonald, Dean-elect of the College of Journalism of Marquette University, with Dr. Ratner for the Center for the Study of Democratic Institutions — the Fund for the Republic, Inc., which authorized a study of the American Character, in 1960. This ageless treatise on medicine received national acclaim at the time of its publication and was subsequently published in **Child & Family** quarterly some twelve years later. In the fourth and concluding installment of the McDonald interview on the traditional and contemporary state of the healing arts, Dr. Ratner warns of what can happen to the physician's professional freedom when "national health agencies prescribe directly to the public via the mass media, and utilize fear and impending drug shortages to motivate public action,"[3] as reflected in the Salk vaccine campaign.

According to Dr. Ratner, the American Medical Association's initial caution on the safety and/or effectiveness of the Salk polio vaccine and its unwillingness to approve of the drug for mass innoculation before reviewing the Francis Report, containing the results and data of the Salk filled trials, was the correct approach.

"But the National Foundation, through a tremendous public relations effort, ultimately isolated the AMA and the physicians of America, picturing them to the public as a group so concerned with preserving their vested interests that they were willing to let children go without this vaccine and become paralyzed."[4] The AMA along with the U.S. Public Health Service and other influential lay groups finally capitulated to the National Foundation was decidedly a political rather than medical act.

". . . the American physician was converted into a technician, a pharmacist's mate . . . there were physicians who suffered from this, physicians who refused to use a vaccine they had doubts about, doubts, incidentally, that were later confirmed — and who refused to be pressured . . . by newspaper headlines or mass communication slogans."

". . . Reputations were in jeopardy, and there was concern over the liability for vaccine-induced cases." And, contrary to public relations jargon the vaccine was **not** "one of the simplest biological preparations to make" but rather it was later recognized by the PHS and the courts to be "one of the most complex biological preparations ever to be made."[5]

Dr. Ratner was careful to point out that the central issue of the controversy was **NOT** the Salk vaccine *per se* nor the personal integrity of Dr. Salk but rather the dangers posed to American medicine by the growing concentration of scientific power in the hands of the few, and the **uncontrolled growth and influence of voluntary health agencies and drug houses.** He notes that Americans as a whole show none of the wholesome wariness towards governmental (and voluntary) health agencies that they might show, for the Pentagon, let's say, and have difficulty conceiving that such important national agencies might be **wrong about health.**[6]

Vaccine Politics

It is a matter of public record that during the scientific fervor over the safety and effectiveness of the Salk formalin-killed vaccine as opposed to the live Sabin vaccine (note: between 1953-1961 the NF supported the Sabin studies with grants of $1.19 million), the powerful National Foundation ran roughshod over its critics including their own researchers such as Dr. Albert Sabin and concerned public health officials such as Dr. Ratner.

One can gleen some insight into the intensity of the intrigue by pro-National Foundation and pro-Salk biographer Richard Carter's rather startling admission that "During the difficult years of 1963 and 1954, when meaningful national trials of the Salk vaccine depended on public confidence in the merits of the undertaking, the National Foundation found it necessary to establish a kind of intelligence network to keep itself posted on Sabin's negative utterances at Medical meetings and press conferences."[7]

History would eventually exhonorate the Sabins and the Ratners of the day against the accusations, and the threats, and public relations barbs of the National Foundation. The Salk vaccine is no longer in use having given way to the Sabin vaccine some years ago.[8]*

The Abortion Controversy

Today, the National Foundation-March of Dimes finds itself embroiled in still another controversy — this time — the debate centers upon the National Foundation's promotion of amniocentesis and intrauterine diagnosis combined with selective related abortion-oriented research and service programs. Yet the Salk experience and the current abortion controversy are not without similarities.

1. **The heavy handedness of the Foundation** towards its Pro-Life critics as exhibited by the Voss memo on **PRO-LIFE AGITATION —**
2. **its insistence that charges made against the NF-MOD are totally without sustance** and are "irresponsible" —
3. **its clever playoff of its Catholic antagonists against the Catholic hierarchy —**
4. and perhaps most importantly — **the repeated refusal of Foundation officials** to face up to its responsibilities and obligations and the challenges posed by medical technical advances — which threaten to subvert the traditional role of the physicians and allied health professionals as healers and teachers, and turn doctors into mere technicians of the State — devoid of personal responsibility and of caritas, of love and "anything less than love in the medical act is pretty inhuman."[9] **All give witness** to the proposition that the time honored lessons to be learned from the Salk debacle have not been learned at all — neither by the National Foundation, nor the medical profession nor government health officials nor the American public. Yet learn we must — If not by our own seeking then by history's imposition of eternal truths — as was the case in Nazi Germany.

* According to a Scripps-Howard / Washington, D.C. news story released on September 24, 1976 in the **Pittsburgh Press,** the Department of Health, Education and Welfare will convene a new national conference on vaccines, which will consider — among other things — the use of the Salk vaccine in the United States.

FOOTNOTES

1. Richard Carter **Breakthrough-The Saga on Jonas Salk —** (Trident Press, N.Y.) 1966 p. 17
2. Ibid p. 17
3. Interview on Medicine — Part IV — **Child and Family** Vol. II No. 4 1972 — Ill. p. 365
4. Ibid p. 364
5. Ibid p. 365
6. Ibid p. 365
7. Carter, R. p. 144
8. For a detailed debate on the medi-politico aspects of the vaccine see "The Present Status of Polio Vaccines". **Illinois Medical Journal,** Vol. 118, No. 2, August, 1960.
9. Ratner Interview — pt. IV p. 371

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INTRODUCTION

On March 16, 1976, George P. Voss, vice-president for public relations — NF-MOD, issued a lengthy memorandum from the National Foundation Headquarters in New York to all NF-MOD chapter executives and field staff re: **PRO-LIFE PROBELM** subtitled **"Pro-Life Agitation."** We reprint here the cover sheet and complete text of the Voss memorandum, with a description of the accompanying attachments.

COVER LETTER

"Enclosed find material that may be of help should a chapter encounter Pro-Life resistance.

Although a number of you have not had any problem, we suggest you file this material against the possible day."

THE VOSS MEMORANDUM — PRO-LIFE AGITATION

The Pro-Life agitation against the March of Dimes has caused a number of our chapters to ask, "How Do You Handle It?"

Because the agitation is often based on different premises in different cities we have attempted to indicate the types of different responses.

At the onset, we should all understand that the more zealous pro-lifers will remain unconvinced that the Foundation is not promoting abortion. This being the case, our efforts should be directed to that majority of our citizens and their leaders who will give fair hearing to the evidence that March of Dimes programs are dedicated to protection of the fetus and improvement of the outcome of pregnancy.

With many Walkathons coming up this Spring, we anticipate that pro-lifers will attempt to persuade Catholic parishes and schools to boycott this important event. If a boycott or other obstructive steps are taken in your area, you should make sure that pastors and principals are aware of the Church's policy concerning the March of Dimes.

The Church's policy, first issued in 1973 and reaffirmed this year, was stated by Cardinal Cody of Chicago on behalf of the National Council of Catholic Bishops. Very simply it is this; no Catholic need contribute time or money to our work, but any Catholic who wishes to may do so in good conscience. A pastor or principal can verify the position by calling Msgr. James McHugh, Director of the Bishops Pro-Life Committee in Washington, D.C., phone (202) 659-6673.

In Michigan the pro-life group circularized the pastors and principals suggesting the March of Dimes be boycotted. Our people reacted promptly and effectively by circularizing the same group with a letter from the State Campaign Chairman (enclosure #1)[1] and the Detroit Chapter sent its own letter from the Chairman (enclosure #2)[2] with a copy of a letter from the Family Life Bureau in Detroit (enclosure #3)[3].

Aside from potential boycotts, we must deal with misinformation directed by pro-lifers at the populace in general. One such piece is their statement that we can't be neutral on abortion since we fund people who are pro-abortion. Enclosed you will find our response (enclosure #4)[4] to be used with clubs, organizations, civil leaderships in whatever community this assertion is made.

Then, too, a favorite line in pro-lifer publications is the one in which they assert that we're all right in the way we promote the care of newborns, but that we "abandon the defective unborn." The implication is that the National Foundation doesn't really do anything for the unborn. In another enclosure (enclosure #5)[5] accompanying this memo you will find a piece that outlines exactly our concern for the unborn and what we are attempting to do for them.

As to the question of amniocentesis, **now** known among certain pro-life critics as our "search and destroy missions:", you all have the results of a survey we did last year on the outcome of amniocentesis. They were impressive and definitely bore out our contention that the technique is most often a life saving one. Use the survey — not necessarily to try to convince a pro-lifer (he won't be), but with the general public. Use the film, "Now That April's Here," with clubs and organizations. And after you screen it for them, quote Dr. Sydney Gellis of the department of pediatrics, Lufts School of Medicine in Boston. "As more and more of these metabolic anbormalities turn up, there will be increasing numbers for which there is a specific therapy," Dr. Gellis says. "Increasingly we shall be looking upon amniocentesis as a technique to support and improve the state of the fetus. Just as it is becoming routine to get a sample of blood from a baby during a mother's labor, so will amniocentesis be used more and more as a means of determining metabolic errors and correcting them during the critical period of rapid growth of the fetus inside the mother."

Finally, have you discussed with your Catholic school system the inclusion of the Nutrition Curriculum Guide in their curricula. It was developed, with a grant from the March of Dimes, by the Catholic University of America. This and other health education materials should provide **a fine method of entry to the school.** (Emphasis added)

Summary of Attachments to Voss Memorandum

1. Letter dated February 11, 1976 **from** William Gallagher, 1976 NF-MOD Michigan Campaign Chairman **to** all Bishops in Michigan Diocese. Mr. Gallagher states that Michigan Citizens for Life charges that the NF-MOD has "sponsored abortion clinics, etc.," and promoted abortion through amniocentesis, are untrue. In contrast, he notes that Msgr. McHugh's investigative findings on behalf of the Bishops' Pro-Life Activities Committee support the March of Dimes program. Mr. Gallagher urges the Michigan Catholic Bishops to offset the MCL campaign by issuing a Diocesan statement on the matter for all parishes.
2. Letter dated February 4, 1976 **from** Richard T. Kelly, Metropolitan Detroit Chapter NF-MOD **to** pastors or principals of parochial schools in Detroit. Mr. Kelly states that John Cardinal Dearden, Archbishop, Diocese of Detroit in a letter of January 30, 1976, assures him that "the action taken by Lifespan in communicating with the parishes of the Archdiocese was done without my knowledge and without my approval. It is clearly not an action that would have been endorsed." Mr. Kelly decries the of Lifespan (MCL) to "cripple" the great works of the MOD by allegedly spreading errors and "irresponsible" charges which misrepresent MOD goals and concerns.
3. Letter dated January 22, 1976 **from** Cornelius J. Van der Poel, S.C. Sp., Director, Family Life Division, Diocese of Detroit **to** Mr. Kelly. Rev. Poel reiterates that Msgr. McHugh — U.S. Catholic Conference Pro-Life Office statement that his (McHugh) investigations assured him that the MOD is not involved in funding "abortion-oriented research projects," and that if abortions were performed after research or after the performance of amniocentesis this was the responsibility of individual physicians. Rev. Poel notes that in his "personal" opinion Msgr. McHugh's original statement of 1973 on the MOD was still valid and that he sincerely hoped the Lifespan action "will not hurt the health and life of many persons who benefit by the research which is made possible through the fundings of the March of Dimes." In a subsequent letter of February 3, 1976, Rev. Poel authorizes the above text to be utilized by Mr. Kelly for the good of the MOD and circulated throughout the parishes of the archdiocese.
4. NF-MOD Statement — **ABOUT GRANTEES WHO MAY BE PRO-ABORTION.** This memo notes that the NF maintains a "neutral" stance with respect to abortion . . . "Legal abortion is outside the Foundation's purview," etc. It concludes, "We observe the laws of the land and under those laws we will not discriminate against one segment (of a pluralistic society) or another because a difference of opinion exists between them."
5. NF-MOD Memo — **HOW THE MARCH OF DIMES PROTECTS THE UNBORN BABY.** A listing of NF-MOD medical service grants for perinatal services and research for fetal diagnosis and treatment.

About This Report

THE VOSS MEMORANDUM is, I believe, an accurate reflection of the National Foundation — March of Dimes public relations back-lash to increasing Pro-Life concerns with specific NF-MOD policies, service and research programs and funding in the United States and abroad.

Since its founding in September 1972, Pro-Life requests to the U.S. Coalition for Life for information on the NF-MOD controversy have out numbered all other requests **combined.** Clearly this investigative report on the NF-MOD is long overdue, and my apologies to those who have been so patient in awaiting its completion.

The bulk of this report covers the NF-MOD policies, programs and research over a nine year period — 1968-1976. Preliminary preparations and interviews for the first section has consumed more than 270 research hours and I expect more than 400 hours will be expended before the final section of this report goes to press.

Part I. of "Who Will Defend Michael?" is designed to give our readers a working frame of reference with regard to past and current Foundation policies, programs and research in the areas of prenatal defects and diagnosis and treatment. Part II will cover specific anti-life programs and research funded by and through the National Foundation and examine the basic moral and philosophical issues which lie at the heart of the March of Dimes controversy.

A special note of appreciation to Father Paul Marx, Director of the Human Life Center, Collegeville, Minnesota and to all the prolife contributors who made this report possible. And to our Coalition volunteer secretarial staff, Patricia Malay and Barbara Kehew for their invaluable assistance in the preparation of this manuscript.

Also, I would like to thank Andrea Caruso of the Division of Health Information and School Relations of the National Foundation-March of Dimes Headquarters in White Plains, N.Y. for her cooperation in supplying this writer with **Facts** booklets and other literature published by the Foundation which made it possible to gain an overall prespective on the NF-MOD programs, policies and research.

RANDY ENGEL
Editor
The Prolife Reporter

September 10, 1976

CHAPTER I

A PRIMER ON THE MARCH OF DIMES ITS POLICIES, PROGRAMS AND RESEARCH

Each year, the National Foundation-March of Dimes National Headquarters issues a basic **FACTS BOOKLET** for its speakers, writers and the contributing public which outlines the overall programs, policies and research of the NF-MOD.

For the introductory section of this report we selected the **FACTS 1968** NF-MOD Booklet as a starting point of our investigation into the March of Dimes controversy. Please note that for the period 1969-76 we have added **only** those items which did not appear in the **1968** version of **FACTS** and/or which indicate a major change in the orientation or emphasis of specific NF-MOD programs or research.
Editor's comments are bracketed in italic.

NF-MOD Definition of Birth Defects

A BIRTH DEFECT IS . . .

Facts 1968 —"A structural or metabolic disorder present at birth whether genetically determined or a result of environmental interference during embryonic or fetal life. Birth injuries are **not** included."

Facts 1970 —"A structural or metabolic disorder, in other words, a mistake in which a body is formed or in the way it functions, that happens as a baby comes into being."

Facts 1971 —"A disorder of body structure, function or chemistry which is present at birth. It may either be inherited or the result of some occurrence during pregnancy.

Facts 1976 —"An abnormality of structure, function, or metabolism. It is genetically determined, or the result of environmental influence on the unborn child. In many cases, a combination of both may be the cause.

- Although the terms "birth defects" and "prenatal defects" will be used interchangeably in this report the later term is a more accurate reflection of MOD's orientation and direction.

Approximately:
* 20% of all birth defects are genetically determined
* 20% of all birth defects are environmental in origin
* 60% result from the interaction of a combination of both influences before birth.

FACTS 1968

NF-MOD Programs, Services, and Research

On January 3, 1968 the NF-MOD celebrated the 30th anniversary of its founding as a voluntary disease-fighting organization dedicated "to leading, directing and unifying" the fight against poliomyelitis. The date also marked the 10th anniversary of the organization's entry into the field of birth defects — The new Great Destroyer.

NF Types of MOD Centers

Treatment Centers — Financed by grants from a chapter or group of chapters of the National Foundation to medical centers or teaching hospitals, these centers provide a wide range of diagnostic and consultative services including in and out patient care and family counseling as well as accredited teaching programs in the area of prenatal defects.

In order to fill 'unmet' community needs and avoid duplication of local, state and national health agency services, priority is given to patients who have a severe and/or unusual birth defect which requires special or complex diagnosis and treatment.

Evaluation Centers — The primary function of the birth defects evaluation center is to establish accurate diagnosis of birth defects and provide counseling and referals when indicated. Like the service-oriented treatment center, they are supported by chapters or groups of chapters of the National Foundation.

Additionally, Chapter Allocations — approved by the chapter's Medical Advisory Committee with the consent of the National Headquarters — may be used to purchase special equipment, provide short-term emergency care and improve the quality of patient and professional services related to the birth defects at local hospitals and medical centers.

Pre-Natal Care and other Educational Programs

The NF-MOD PNC Program, initiated in 1965, is conducted largely through volunteer efforts and stresses the importance of preventative care and the monitoring of pregnancies of "high risk" patients. It is part of a larger educational effort directed by the NF-MOD which includes the publication and/or distribution of laymen and professional publications, films, exhibits, and the sponsorships of conferences, seminars and symposia related to birth defects.

NF-MOD Statistics on Birth Defects

According to the FACTS booklet for 1968, an estimated seven per cent of all infants born in the U.S. have defects detectable at birth or in the first year of life, that is 250,000 babies born *annually* with defects based on the annual U.S. birth of 3.6 million children. Birth defects claim some 560,000 lives each year — 60,000 deaths among children and adults, plus as estimated half million still births, miscarriages and spontaneous abortions.

Gains In The War Against Birth Defects

Five main areas of promise in the NF-MOD battle singled out for special attention in the 1968 Booklet with **emphasis on EARLY diagnosis, treatment and rehabilitation included:**

1. **EXCHANGE TRANSFUSIONS** *before* and at birth to combat **RH Factor Incompatability.**
2. **EARLY DETECTION AND TREATMENT OF INBORN BODY CHEMISTRY ERRORS.**
3. Development and field testing of **Rubella** (German Measles) Vaccine.
4. **Corrective Surgery** and improved treatment and rehabilitative techniques and service for the victims of congenital heart defects as well as open spine (Spine Bifida) and water on the brain (Hydrocephalus).
5. Advances in **Genetic Counseling** made possible by increased knowledge of chromosomal abnormalities and new techniques to determine carriers of recessive traits.

FACTS 1969

FETOLOGY and **Pediatric surgery** on the newborn are examined in the 1969 Facts booklet as well as **AMNIOCENTESIS** for purposes of prenatal medication, transfusions and surgery [*Editor's Note — procedures normally carried out in the* **third** *trimester of pregnancy.*]

THE NADLER GRANT

The 1969 Facts Grant Index includes a $27,964 National Foundation grant to Henry L. Nadler, M.D. of Children's Memorial Hospital in Chicago, Ill. for —

"THE DEVELOPMENT OF SIMPLE AND SAFE METHODS OF AMNIOCENTESIS and the development of improved culture techniques to detect prenatal chemical and chromosomal defects for the purpose of prenatal treatment of the defective child in the future." The abstract also notes that amniocentesis can be done "quite safely early in pregnancy."

Dr. Nadler was one of the first National Foundation grantees to expand the scope of intrauterine diagnosis within the NF-MOD program.

PRENATAL CARE PROGRAMS

New emphasis on youth participation in comprehensive prenatal care education, with emphasis on the dangers of drug misuse, **SELF-ABORTION,** *(emphasis added)* and the importance of prenatal care of very young mothers.

FACTS 1970

- **NEW EMPHASIS ON THE PREVENTION OF BIRTH DEFECTS**

Before Conception	Before Birth
1. Genetic counseling	1. Medical supervision of drugs during pregnancy
2. Rubella and RH Vaccine	2. Proper medical care during pregnancy
3. Proper nutrition	3. Amniocentesis in conjunction with prenatal treatment for 'in-womb' therapy
4. Proper medical care and treatment	

- Improved Patient and Diagnostic Services — The development of a **Syndrome Identification and Consultation Service** at Boston Floating Hospital for Infants and Children — a free national mail service to assist physicians in the diagnosis of rare or unfamiliar birth defects.

[• *Amniocentesis is now mentioned with increasing frequency, but still within the context of early diagnosis and treatment. The unborn child is referred to as the patient in the womb.*

In the section on genetic counseling and Down's Syndrome (Mongolism) however, a veiled specter of selective abortion following amniocentesis and diagnosis of the defect is alluded to in an open ended case study in which the pregnant woman is a carrier of the hereditary form of mongolism and undergoes amniocentesis to enable her physician to determine whether her unborn child has Down's Syndrome.]

- Genetic Counseling is expanded to more than 50% of the NF-MOD Birth Defects Centers.
- **ABORTION LINKED TO SECOND TRIMESTER AMNIOCENTESIS**

While **Amniocentesis: In the womb diagnosis** is presented in a positive manner i.e., within the context of fetal therapy on pages 11 and 68 of the Facts 1971 booklet, page 64 describes the **NF-MOD Prenatal Birth Defects Prevention Center** at Johns Hopkins which entered full-scale operation in June 1969 as follows:

> "Using the technique of amniocentesis — on pregnant women when there is reason to doubt whether the child will be born healthy, the Center staff can identify many chromosomal, sex linked and enzymatic-metabolic defects in the unborn child. If evidence shows the fetus to be abnormal, the parents **may consider termination of pregnancy.**

KEY RESEARCH GRANTS

- **EPSTEIN** — In the Research Grant section (p. 30) a NF grant of $22,824 is awarded to Charles J. Epstein, M.D., of the San Francisco Medical Center, University of California for studies related to chromosomally-abnormal cells and the nature of abnormal metabolism in the defective cells.

  ". . . He is looking for evidence of generalized abnormality of RNA and protein synthesis in cells from patients and **ABORTUSES** with chromosome defects . . ."

- **NADLER** is awarded $49,773 for **continuing** research on amniocentesis by the National Foundation.

New avenues of research are opened in the areas of RDS (respiratory distress syndrome), Lesch-Nyan disease — a sex linked inborn metabolic error affecting males, cystic fibrosis, and diabetes.

FACTS 1971

FACTS 1972

- A new category of investigative research is opened called **"CELLULAR ENGINEERING"** directed at immunological deficiency diseases such as agammaglobulinemia which prohibits the infant's blood from manufacturing gamma globulin. The proscribed treatment — bone marrow transplants to the affected infant.
- 42 B.D. Research projects awarded by the NF Board of Trustees acting upon the recommendation of its president and Scientific Advisory Committee.
- 112 medical service programs expand the NF-MOD Birth Defect Programs.
- 200 genetic counseling centers established in the U.S.
- **All references to abortion are erased** from the description of the Johns Hopkins program (p. 36)
- **Epstein** receives a continuing grant of $14,883 but no mention is made of **abortuses** as a source of defective chromosomal cells for his research program.
- **Nadler** awarded a continuing grant of $50,284 for amniocentesis study. Additional grants related to prenatal diagnosis to detect prenatal defects are expanded to include other researchers.

FACTS 1973

- Introductory language takes on a decidedly new public relations thrust with emphasis on the role of the Foundation in protecting "the youngest and most defenseless members of our society, the unborn, the new born." The NF-MOD "is one expression of the protective instinct of the American people," The Battleground of the NF-MOD's new war against birth defects begun in 1958, will be the laboratory and clinic. ". . . Call us the conscience of America in guarding the health of its children." However . . .

FORMAL ABORTION STATEMENT

- Under the title **TREATING BIRTH DEFECTS — Prenatal diagnosis of birth defects** — the National Foundation makes the most explicit statement on abortion thus far in a Facts booklet.

"Until recently, when some birth defect was suspected, the parents often had to decide, purely on the basis of the statistical odds, whether or not to terminate the pregnancy. As a result, because of the fear that the unborn child *might* be defective, many normal pregnancies were needlessly aborted. **Today, some birth defects can be detected early in pregnancy through amniocentesis,** a painless procedure in which a needle is inserted through the pregnant woman's abdomen and into her uterus to withdraw a little of the fluid surrounding the fetus. Amniocentesis can **definitely** establish whether the fetus has the defect, so that a parental decision can be based on knowledge instead of speculation. **In no event, however, may March of Dimes funds be used to pay for an induced abortion.** Prenatal detection of some defects also enables doctors to begin treatment right from the moment of birth, sometimes even before."

- Evidence of the growing trend **towards** prenatal diagnosis (combined with selective abortion for affected children) and **away** from basic treatment of birth defects *per se* is most explicit in the listings of the services provided under the 100 NF-MOD Medical Service Programs throughout the United States, and in the research abstracts provided on the NF's 56 Birth Defects Research projects.

The NF-MOD Medical Service program is generally **administered** by medical centers or schools and designed in cooperation with chapter officials and medical advisory committees.

Newly funded Foundation researchers in the specific areas of **amniocentesis and tissue culture and prenatal diagnosis include:**

William L. Nyhan, M.D., Ph.D., U. of California, San Diego	$40,000
David G. Nathan, M.D., Children's Hospital Ct., Boston	25,000
Vivian E. Shih, M.D., General Hospital, Boston	11,780
Maria L. New, M.D., Cornell University, NYC	30,240
John F. Bertles, M.D., St. Luke's Hospital, NYC	56,925
C. Ronald Scott, M.D., U. of Washington, Seattle	30,000

The specific defects associated with the above grants include **sickle cell anemia, cystic fibrosis,** and **chromosomal defects such as Down's Syndrome.**

New and continuing Foundation Birth Defects grants include:

H.L. **Nadler**	$44,064	N. **Kretchmer**	$30,000
O.J. **Epstein**	25,474	V.A. **McKusick**	43,859
D.L. **Rimoin**	35,923	M. **Winick**	42,162
O.J. **Miller**	47,481	L. **Pauling**	14,548

- **Expansion** of prenatal care programs in schools and teen programs; nurse-midwife program; publications — reprint series, original article series, International Directory of Genetic Services; films and audio-visual programs including "Tomorrow Happens Today".

FACTS 1974

- **Reference to abortion,** found in 1973 Facts booklet is **removed** from section of amniocentesis and prenatal diagnosis. The assertion that amniocentesis **"definitely"** can establish whether a fetus has certain defects, **remains in tact,** followed by the note that **some** of these defects can be treated at or before birth.
- Included for the first time in the medical service programs (MSP) section which lists the institutions receiving the funds, amount, and statement of purpose is the **names of the institution's program director. For example:**

  Dr. Charles Epstein is listed as receiving a $35,000 grant for genetic diagnosis and counseling under the MSP at S.F. Medical Center while his research grant of $25,474 is extended to June 30, 1974.

  William L. Nyhan is listed as receiving a $15,000 grant for a genetic clinic at Children's Health Center in La Jolla, California and a $40,000 research grant for prenatal diagnosis at the U. of California, San Diego.

  David L. Rimoin, M.D., Ph.D. receives $35,723 for prenatal diagnosis and Tay-Sachs screening program at Harbor General Hospital in Torrance, California and a $54,817 research grant at Harbor General for dwarfism diagnosis and treatment.

  It should be noted therefore, that the Medical **Service** recipient doing screening and counseling and the NF-MOD researcher doing the amniocentesis, diagnosis and referrals at the same or nearby medical facilities may be **one and the same person.**
- A $9,240 research grant to Peter A.J. Adam. M.D., case Western Reserve University, Cleveland, Ohio for investigation of fetal glucose metabolism, in collaboration with the U. of Helsinki in Finland.
- New NF-MOD Programs include:
  - —Basil O'Connor Starter Grants for promising young scientists in the field of birth defects.
  - —Training and preparation for parenthood programs.
  - —Operation Stork, BIB (Better Infant Births) and Dial-the Doctor — PNC programs.

FACTS 1975

- As in the previous issue of **Facts** all references linking abortion to amniocentesis and prenatal diagnosis are removed. For the first time, however, the section on RH incompatibility notes that the RH vaccine must be administered within 72 hours after the delivery or miscarriage of each RH positive fetus and **AFTER ANY ABORTION** — no matter whether it is her first, fifth, or her tenth pregnancy.
- Pattern of expansion in areas of prenatal diagnosis services, facilities and research projects especially related to **Sickle Cell Anemia, Tay-Sachs** disease and **Thalassemia** (Cooley's anemia) and PNC education programs related to **Rubella** and **venereal disease** and **teenage pregnancy.**
- **Medical Service Program Grant recipients** for their respective institutions include:

H.R. Giles, Arizona	$25,987
W.L. Nyhan, California	34,967
D.L. Rimoin, California	34,995
Y.E. Hsia, Connecticut	30,000
K. Hirchhorn, N.Y.	20,790
D.B. Shurtleff, Washington	96,195

●●Also two MSP grants to two geneticists known for their pro-life sentiments:

Hymie Gordon, M.D., Mayo Clinic	$ 6,000
Ken Garver, M.D., of Pittsburgh	25,052

- Among the 116 recipients of NF **Starter Grants**(s) for young scientists and NF Basic (b) and Clinical (c) Grants to tally $3.9 million are:

YALE UNIVERSITY
SCHOOL OF MEDICINE — $17,798
New Haven — Starter

Maurice J. Mahoney, M.D.

To identify the basic defect in two inherited disorders of vitamin B12 metabolism, and to develop means of carrier identification, early diagnosis, and possible treatment of the affected unborn or newborn child.

J. Salk, California	($115,000) B
M. Golbus, California	(30,756) B
M. Golbus, California	(16,500) S
L. Pauling, California	(24,000) B
M. Kaback, California	(47,037) B
D. Rimoin	(60,000) B
H. L. Nadler	(70,000) B
D. G. Nathon	(37,655) B
L. Cederquist	(25,000) C
J. F. Crocker	(9,500) B

●●Also a Basic Grant of $37,908 to Dr. Dennis Cavanagh of St. Louis University.

FACTS 1976

- **Medical Service and Research Grants Recipient listings** omitted from Facts Booklet 1976 but is made available separately on request from the Public Relations Department, NF headquarters.
- **Big Jump in National Foundation Medical Services Program** from 159 programs in 1975 to 250 in 1976.
- **The section on Prenatal Diagnosis of Birth Defects** mentions two noteworthy items:
  —Drs. Tanaka, Ampola, and **Mahoney** of Yale U. School of Medicine, New Haven "Saved an infant from a fatal inherited disease through prenatal diagnosis and treatment. The child today is a healthy toddler."
  —A National Foundation survey of 37 institutions providing amniocentesis highlighting "the life-saving potential of amniocentesis" among patients at risk of genetic disease. [*Of the 2,000 women tested 97% carried a normal child. Of the remaining 64 affected unborn children all but two were aborted.* **(1) Who then will defend the right to life of the defective child.[2] (2) What kind of 'advocate' for the defective child can express enthusiasm for a study which indicates that virtually 100% of the affected children were killed in the womb? (3) If the MOD professes to be an advocate for HEALTHY preborn children only, who needs it?**]
- New Grant Listing for Professional Education and Health Personnel Development Grants.
- Recipients of NF Medical Service Programs Grants 1975-76 include:

W.L. Nyhan, California	($32,942)
C.J. Epstein, California	(35,000)
D.L. Rimoin, California	(39,995)
Y.E. Hsia, Connecticut	(32,013)
M. Feingold, Maine	(52,760)
K. Hirschhorn, N.Y.	(23,424)
M. Steele, Pennsylvania	(16,879)
D.B. Shurtleff	(13,986)
•H. Gordon, Minnesota	($ 6,000)
•K. Garver, Pennsylvania	(27,142)

- Recipients of NF Starter, Basic, and Clinical Grants for 75-76 include:

Maurice J. Mahoney — $43,170) B
Yale U. — New Haven

Wm. N. Spellacy — ($10,000) B
Gainsville — U. of Florida

M. Golbus, California	($34,902) B
M. Golbus & D. Stites	(23,765) B
M. Kaback, California	(50,624) B
D.L. Rimoin, California	(40,000) B
H.L. Nadler, Illinois	(70,000) B
D. Hollingsworth, Ky	(30,000) B

Foreign grants to researchers in Canada, Helsinki, Jerusalem and Stockholm.

- Excelleration of School Health Education Programs
  —Curriculum Guide for Health Education: Nutrition — prepared through a NF grant to the Catholic University of America for parochial secondary schools.
  —A $75,000 grant to the **Education Development Center** of Cambridge — [*Editor's Note: architects of the M:ACOS program*] — for a secondary school curriculum. "Will Our Children Be Healthy?"

CHART I
U.S. COALITION FOR LIFE — FACT SHEET NF-MOD

Year	Number of Research Projects Funded - NF	Number of Evaluation Centers	Annual[1] Cost of Medical Care Programs	Number[2] of Patients Served Annually	Annual[3] Cost of Research Program	Annual Cost of Education Programs	Number of Birth Defects Centers	Annual Cost of Birth Defect Centers	Annual Funding of Polio Patient Aid	CHAPTER ALLOCATIONS For Patient Care	For Professional Personnel	For Equipment
1967	14	30	$5.7M	—	$4.8M	$3.4M	92	$2.7M	$2.1M	18	8	2
1968	15	39	$5.7M	—	$4.7M	$4.2M	103	$2.9M	$1.6M	17	7	1
1969	25	—	$5.8M	—	$5.2M	$4.4M	111	$2.8M	$1.5M	18	9	1
1970	32	—	$5.0M	—	$4.3M	$4.4M	104	$2.8M	$1.3M	25	N/S	N/S
1971	42	—	$5.4M	—	$4.5M	$4.9M	112	$2.2M	N/S	N/S	N/S	N/S
1972	56	—	$5.6M	10,000	$4.3M	$5.6M	100	$2.5M	N/S	N/S	N/S	N/S
1973	68	—	$6.8M	10,000	$4.6M	$6.7M	118	$2.5M	N/S	N/S	N/S	N/S
1974	116	—	$6.5M	15,000	$6.1M	$8.6M	159	$3.6M	N/S	N/S	N/S	N/S
1975	285	—	$8.5M	25,000	$9.7M	$10.5M	228	$5.1M	N/S	N/S	N/S	N/S

•Source - MOD-NF Facts Booklets (1968-1976)
Figures Rounded off to nearest $100,000

1. Total Medical Care Funds - 1938-75 — $459.7 Million
2. Total Number of Patients Served - 1938-72 — 350,000 Persons
3. Total Research Funds - 1938-75 — $137.0 Million

A(-) or N/S indicates no statistics available for that period.

CHAPTER II

NATIONAL FOUNDATION — MARCH OF DIMES THE POLICY MAKERS

The business and affairs of the National Foundation is managed by a **Board of Trustees** — from 5 to 50 in number elected at the annual Fall meeting of the Corporation. An Executive Committee of not more than nine (9) Trustees serve in an advisory capacity to Corporate officers.

The chief executives officer of the Foundation is the president — a position currently held by **Joseph F. Nee.** Chairman of the Board is **Harry E. Green.** Salaries and compensation of all officers and staff are fixed by the Board of Trustees.

Advisory Committee — In addition to various committees of the Board of Trustees, there are a number of specialized NF Departments (research, chapter volunteers, medical services, public relations, etc.) and advisory committees for evaluating, designing, and selecting grants for BASIC RESEARCH — CLINICAL RESEARCH and BASIL O'CONNOR STARTER RESEARCH programs. A Medical Service Advisory Committee determines the merit and appropriateness of proposed medical service programs.

Annual Report — The names of Trustees, national officers, staff and scientific-medical advisory members as well as Foundation policies and programs and annual budget are found in the Foundation's **Annual Report** available on request from National Headquarters.

Current 1975-76 advisors to the National Foundation covered in this report include:

Kenneth J. Ryan, M.D.
Henry L. Nadler, M.D.
William L. Nyhan, M.D., Ph.D.
David Rimoin, M.D., Ph.D.
William Spellacy, M.D.
Kurt Hirschhorn, M.D.
David G. Nathan, M.D.
Myron Winick, M.D.
Orlando J. Miller, M.D.
Sydney S. Gellis, M.D.
Victor McKusick, M.D.
Leon Rosenberg, M.D.

CHAPTER III

1973 NATIONAL FOUNDATION POLICY ON ABORTION

On March 19, 1973, Vice President for Public Relations, **George Voss,** issued to all chapter chairmen a statement of the **Official Position** of NF with respect to abortion, with subsequent distribution to NF-MOD medical, public relations, staff and volunteer personnel.

> Legal abortion is outside the Foundation's purview. We are incorporated for only one purpose, namely: to support medical scientific research and treatment leading to the prevention or amelioration of the serious consequences of birth defects.
>
> The tax exempt status of the National Foundation is based in part on the requirement that the Foundation shall refrain from lobbying with governmental authorities to enact legislation either anti or pro abortion.
>
> Neither the Foundation nor its component Chapters finances abortion or abortion research. Further, it is the Foundation's belief that a decision to terminate a pregnancy should **not** be directed by any scientist, physician, or other persons providing genetic services.

Two years later, on August 13, 1975, Mr. Voss issued a Restatement of NF Policy on Abortion with the following addition —

"Patients receiving prenatal diagnostic services in a Foundation-sponsored program cannot be required to give prior consent to the performance of an abortion as a condition for the provision of such diagnostic service."

Additionally, a two page memo on **Amniocentesis** is in circulation listing the reasons the NF supports this technique, namely

1. For prenatal management of RH disease
2. Prenatal detection of fetal defects to be treated at or before birth
3. As a determinate of fetal lung maturity and/or fetal distress
4. Makes possible early familial adjustments . . . financial, etc.
5. **Prevents** the abortion of normal pre-born children who might otherwise have been aborted on a statistical basis alone.

6. Amniocentesis research provides valuable knowledge in the understanding, diagnosis and possible treatment of genetic defects.

Both the 1973 and 1975 memos have been widely distributed by the NF and MOD Chapters to the general public and have received wide circulation in diocesan newspapers across the U.S. and Canada.

The Official Catholic Response

On November 7, 1973, The Family Life Division of the U.S. Catholic Conference, directed by Msgr. James T. McHugh, issued a position paper on the **NF-MOD and Abortion** based upon

- The results of NF senior officials meeting with Msgr. McHugh on October 17, 1973, at which time the NF pledge to "carefully scrutinize and monitor all its research proposals to insure that they are not directed toward encouraging abortion" and to co-operate with the USCC/Family Life Division, in the future, on policy developments and moral and ethical issues.
- The findings and analysis of Rev. Bruce Williams on the NF-MOD policies,programs and research on amniocentesis and abortion which appeared in the **Homiletic and Pastoral Review** of October, 1973.

The Williams Report on Amniocentesis and The March of Dimes

The Williams article is vintage Voss — a restatement of the NF policy of "no policy" warmed up on a theological hot plate which is not surprising since 14 of the 28 references bear the official National Foundation's imprimatur or that of its researchers.

Straw-babies are set up and quickly blown down. Williams claims —

— amniocentesis has therapeutic purposes which should **not** be obscured by the abortion debate.

— amniocentesis is **not** merely a code word for selective abortion

— amniocentesis is **not** inherently unmoral

— amniocentesis can assist in familial preparation for an afflicted child

— the Foundation's tax status (501 (c) (3)) would be jeopardized by adopting any stand on legalized abortion

— before the advent of prenatal diagnosis, normal pre-born children were aborted on statistic basis alone — amniocentesis now spares the life of a **normal healthy** child

— the MOD has shown itself to be more than willing to listen seriously to the problems brought forward by pro-life people and, where appropriate, to modify its procedures accordingly. A negative posture towards the MOD should be avoided.

Rev. William's conclusion reads in part

> **"We have seen that the March of Dimes pursues only good objectives through means which are also, in themselves, good. The prospect that ABORTION may OCCASIONALLY INTRUDE, to a very MINOR EXTENT and in a way undesired by either the Foundation or its pro-life contributors, is not an automatic warrant for these contributors to cease their support."**

Msgr. McHugh reaches essentially the same conclusion —

"... it seems clear that co-operation of Catholic groups and schools with the MOD is morally permissible because the MOD does not fund, sponsor or directly encourage abortion."

McHugh Update — 1975

On March 11, 1975, seventeen months after the original McHugh memorandum, a confidential memo was distributed to all Catholic Bishops in the United States by Msgr. McHugh assuring the hierarchy that the NF had consulted with the Committee for Population and Pro-life Activities of the USCC (formerly The Family Life Bureau) and had taken efforts to manifest "a more visible Prolife image."

However, some recalcitrent prolifers were continuing to urge withholding support for the MOD making it necessary for Msgr. McHugh to repeat —

- At present, the accusations against MOD are without foundation —
- The Church should take a neutral position in regard to the March of Dimes —
- The conclusions of the paper — NF-MOD and Abortion, November 7, 1973, still stand.

Continuing Catholic Support 1976

On May 20, 1976 the National Foundation released a formal statement from its **Board of Directors** on **POLICY CONCERNING PRENATAL DIAGNOSIS OF BIRTH DEFECTS USING AMNIOCENTESIS.**

This statement goes beyond earlier NF press releases from Voss's office and examines the rationale, safety and reliability of amniocentesis and matters related to genetic counseling and directives in relation to the patient.

In summary, the National Foundation pronounces amniocentesis for the purpose of intrauterine diagnosis (presumably the procedure would be carried out primarily in the second trimester of pregnancy), a safe and reliable diagnostic tool in reliable medical hands. The role of the attending physician is seen primarily as one of presenting scientific information and explanations to the patient and her family. The doctor may

not give directive advice concerning abortion in individual cases.

The statement concludes that all NF-MOD grantees are required to state their willingness to abide by Foundation policy when using NF-MOD funds to provide prenatal diagnostic services.

Not too surprisingly, only one month later, Msgr. McHugh's office issued a vigorous defense of amniocentesis in a 1200-word statement which appeared in a number of diocesan papers and national Catholic weeklies titled "Amniocentesis — A Life Saving Technique". Additionally, he notes a recent foundation grant to provide initial funding for a long-range study to determine the implications of abortion in subsequent pregnancies. Msgr. McHugh, however, fails to name the researcher in charge of the study — a one Kenneth J. Ryan, M.D. a member of the NF's Basic Research Advisory Committee, and a well-known abortionist holding positions at both Harvard Medical School and Boston Hospital for Women. We will deal with the Ryan grant (totalling $500,000 for 5 years) and the issue of the effects of induced abortion on subsequent births, in Part II of this report.

March for Life or Death?

In May, 1973, the U.S. Coalition for Life published its first official policy statement on the Foundation controversy advising the withholding of financial and volunteer support until such times as the National Foundation did an about face on its growing anti-life orientation manifested in The NF Original Articles Series of April, 1971, on "Intrauterine Diagnosis and Selective Abortion" as well as pro-selective abortion statements by MOD-NF funded geneticists including Charles J. Epstein, M.D. of the University of California, San Francisco.

Over the last three years Prolife concerns have been echoed in public statements of a large number of prolife national spokesmen including Rev. Paul Marx, author of **The Death Peddlers** and **The Mercy Killers,**[2] Dr. Frank Felici, professor of biology at the University of San Francisco and a founder of Scientists for Life,[3] and Dr. John C. Willke, author, lecturer and President of Greater Cincinnati Right to Life and an officer of The National Right to Life Committee.[4]

On April 9, 1976, Bishop Walter L. Sullivan of Richmond, Virginia, released the findings and recommendations of the diocesan Medical Ethics Commission investigating alleged links of the NF-MOD with abortion at the regional level. Support of the Richmond Diocese has been suspended until the NF's espoused philosophy and grant procedures prohibiting pro-abortion directives have been thoroughly implemented at the regional level.

THE END OF THE BEGINNING

Thus far we have attempted to present the reader with some basic facts and documents and policy statements representing two particular points of view concerning the direction and policies of the National Foundation-March of Dimes.

Let's start now to examine from a variety of perspectives some of the basic issues of the controversy beginning with the matter of amniocentesis.

CHAPTER IV

THE HISTORY OF AMNIOCENTESIS . . . HISTORY — WHAT HISTORY?

"Amniocentesis, from the Greek roots **amnion** for lamb, and **kentesis** for puncture, entails inserting a hollow needle through the abdominal and uterine walls into the amniotic sac and withdrawing fluid and cells shed by the fetus . . . the image of the sacrificial lamb conjured up by the Greek etymology of "amniocenthesis" is more than accidental; in order to allow the birth of those free of genetic disease, it is necessary to kill those affected by it."[5]

The use of amniocentesis as a clinical procedure dates from 1882, when it was introduced as a treatment via the transabdominal route for polyhydramnios (excess accumulation of amniotic fluid) by Schatz.[6] This most elementary historical footnote no doubt will come as a surprise to those who perceive the procedure as being a modern medical tool.

There is no evidence that animal studies were conducted prior to that time, and comparatively little research has been done on amniocentesis as a procedure apart from its applications.

In the 1930's the development of amniography made possible the visualization of fetal soft parts and localization of the placenta.

These early applications were strictly therapeutic — that is — amniocentesis was carried out as a potentially lifesaving procedure on the unborn child whose life would otherwise be severely jeopardized. **IT WAS FOR USE IN LATE PREGNANCY AND IN LABOR.**

Amniocentesis advances prior to 1967 followed two main avenues of research — **RH Isoimmunization (see Chart II) and the assessment of fetal maturity related to respiratory distress syndrome** (RDS) a major cause of neonatal mortality and an important threat to a prematurely born infant. Ninety-five percent of infants who die of RDS are premature.[10]

RH-ISOIMMUNIZATION — MEDICAL MILESTONES[9]

1930-40's	Discovery of the RH factor and recognition of major blood groups (A, B, and O)
1941	Levine demonstrates that RH sensitization in an RH negative mother to an RH positive fetus was responsible for the disease pathologies associated with erythroblastosis fetalis.
	Simultaneously experimentation begun on exchange transfusions of the affected neonate shortly after birth.
1950's	Development of procedures and tests to demonstrate the presence of fetal erythrocytes in the maternal circulation.
1956	Works of Coombs and Fuchs leads to development of techniques to detect A and B antigers in amniotic fluid cells which were of fetal origin.
1963	Liley attempts first intrauterine transfusion of blood into the fetal abdomen.
1965	Liley's discoveries lead to the management of RH isoimmunization via amniocentesis and intrauterine fetal blood transfusions — a milestone in the history of amniocentesis.
1964-68	RH vaccine (RhoGAM) prepared from concentrated gamma globulin developed for the protection of RH negative women following an RH positive birth.

Other Amniocentesis-Associated Findings, however, would eventually lead **away** from the treatment of an afflicted neonate and **towards** his destruction —

1955	Development of the anenatal determination of fetal sex in amniotic fluid, which later would be used for the prenatal diagnosis of sex-linked diseases.
1965	The first unborn error of metabolism was diagnosed via amniocentesis by Jeffcoate leading to the possibility of early cortisone replacement therapy for adrenal hyperplasia.
1966	Achievement of the successful culturing of fetal amniotic fluid cells in sufficient quantity to permit karotyping of the cells.
1967	Jacobson and Barter publish an article which postulated the management of genetic defects via amniocentesis; "including the diagnosis of chromosmal translocations which had been substantiated by Jacobson and Turner one year earlier.

AMNIOCENTESIS AND ABORTION

THE IMPLICATIONS OF THESE FINDINGS WERE OBVIOUSLY NOT LOST ON RESEARCHERS and in 1968 **Acta Pathologica et Microbiologica Scandinavia** set the stage with the observation that

> "If cells of fetal origin may be procured safely from a sufficient early stage of development, and if legislation permits therapeutic abortion in cases of eugenic risk, pregnancy may be interrupted when the fetus is found to be genetically defective . . ."[12]

VALENTI AND NADLER

That same year, 1968, Dr. Carlo Valenti of Brooklyn's Downstate Medical Center carried out the first "therapeutic" abortion of a Down's Syndrome fetus in the second trimester of pregnancy following the culture of karotyping of fetal cells obtained by amniocentesis.[13]

Also in 1968, **Dr. Henry Nadler** of Children's Memorial Hospital, Chicago, successfully diagnosed Down's Syndrome at 10 weeks gestation by chromosome analysis of cultivated amniotic fluid cells obtained just prior to the "therapeutic abortion."[14] Soon after, Nadler would receive a $27,964 National Foundation Grant for Pre-Natal Diagnosis and Cell Culture to detect chromosomal defects and inherited metabolic diseases.[15]

NF-MOD A CHANGE OF DIRECTION

The late 1960's marked a significant change in the orientation of amniocentesis as a diagnostic tool. As we will see shortly, the late 1960's also marked a turning point in the liberalization of abortion laws in the U.S. During this very short span of time we also note, the National Foundation announced the Nadler grant with its emphasis on the intrauterine diagnosis of prenatal defects early in pregnancy — defects for which in the majority of cases there was no known therapy or treatment for the preborn patient in the womb.

It is therefore highly **unlikely** that the gradual transformation of amniocentesis from a life-saving to life-taking technique for defective children could have possibly escaped the attention of the National Foundation. Rather, we suggest that the National Foundation was fully aware of the implications of amniocentesis and selective abortion and that it found no contradiction between its role as an advocate of the defective child and its sponsorship and encouragement of early amniocentesis, diagnosis and the killing of the affected child in the womb.

It is imperative at this point to RE-EMPHASIZE the fact that amniocentesis for purposes of RH immunization or assessment of fetal maturity, resembles amniocentesis for detection of genetic defects ONLY insofar as the technique of extracting amniotic fluid is the same. There is a radical departure, however, in terms of timing and intent between the former and the latter — a critical distinction not made clear in the writings of Williams and McHugh on amniocentesis.

Because the PRIMARY orientation of RH and RDS therapy is truly THERAPEUTIC; i.e., for the benefit of the unborn child, amniocentesis is almost always carried out in the THIRD TRIMESTER of pregnancy when more amniotic fluid is available for examination and there is less danger of puncturing some other abdominal organ. In this case "the later the better" principle holds true in general practice. Hundreds of thousands of these procedures have been done around the world with an extremely low rate of maternal and fetal complications.

Where amniocentesis is carried out, however, for the detection and diagnosis of prenatal defects combined with 'selective abortion,' a COMPROMISE on risks and timing must be reached. In this case, the principle of "the earlier the better" holds true since the incidents of maternal complications from abortion — both physical and psychological — rise sharply in the second and third trimester of pregnancy. Hence, the procedure must be accomplished — LATE ENOUGH in the pregnancy to secure a sufficient quantity of amniotic fluid for an adequate diagnosis but EARLY ENOUGH to permit the abortion of an afflicted pre-born child with the least risk to the mother, that is between the 14th and 17th week of pregnancy.

NOTE: Although amniocentesis as a procedure is usually associated with the withdrawal of amniotic fluid, the identical procedure may be used to instill fluid directly into the amniotic cavity as with the installation of saline solution commonly used to induce 2nd trimester abortions. The procedures are identical in terms of technique.

CHAPTER V

SELECTIVE ABORTION A TEMPORARY OR PERMANENT FIXTURE?

The question of whether or not selective abortion would become a **permanent** component of genetic therapy or serve as a **temporary** solution awaiting new developments in the treatment of inheritable prenatal defects, was raised by NF-MOD researcher, Henry Nadler, in a late 1968 issue of **Pediatrics.**

According to Nadler, the prevention of defective children via selective abortion is a necessary stage that would ultimately be supplemented by the genuine therapies developed as a result of continuing research or early diagnosis.[16]

Other geneticsts disagree.

Writing in the **New England Journal of medicine** in the Spring of 1969, John Littlefield editorializes on the need for lawful "therapeutic" abortion and clearly states that while genetisists may hold out for some occasional breakthrough leading up to therapy for the fetus, society and the profession's must appreciate and accept that the proper therapy now is for the family, and at times that means abortion . . ."[17]

This view — holding that the hope for treatment of most genetic disease IN UTERO is unrealistic and untenable and that ABORTION would remain the treatment of choice for most inheritable diseases in the foreseeable future — was shared by Valenti — and eventually by Nadler too! (See Nadler at the Ross Conference.)

A somewhat updated version of the genetic themesong — "Abortion is here to stay" was echoed by **Professor Arno G. Motulsky** of the Department of Genetics, University of Washington, in Seattle, in **Science** magazine in August, 1974. The article titled "Brave New World?" is adapted from an address which was to be published as part of **the Proceedings of The Fourth International Conference on Birth Defects,** held in Vienna, Austria, September, 1973, and **sponsored by the National Foundation-March of Dimes.**

According to Motulsky, a self-professed "philosophic utilitarian", the view that selective abortion after intrauterine diagnosis is only an "interim measure" is "probably unrealistic." That is

> *"Effiacious treatment for a complex defect such as Down's Syndrome and similar structural defects is difficult to imagine. Many types of existing and future postnatal therapies cause a certain amount of suffering in the child. Prenatal therapy applied to the fetus may be dangerous to the mother also. Therefore, EVEN when effective treatments for more birth defects have been developed, many parents will prefer a safe abortion with the assurance that their next child will not be affected with the disorder for which selective abortion was performed. This means that abortion for genetic defects discovered by intrauterine diagnosis is here to stay for a long time."*[24]

Dr. Motulsky readily agrees that the development of intrauterine diagnostic methods, such as amniocentesis, have revolutionized genetic counseling, but he also raises the issue as to why we must go through the trouble and expense of doing intrauterine tests that might harm a healthy fetus, if inspection of the infant and diagnostic tests at birth would be much easier. An infant with serious birth defects could be "terminated" at that time.[25] The latter suggestion is footnoted by Motulsky as follows (30) F. Crick, cited in **Nature** (Lond.) 220, 429 (1968). Francis Crick is the world famous Nobel prize winner and non-resident Fellow of The Salk Institute, founded and sustained by The National Foundation.

On the issue of abortion as a method of eliminating defective children, Motulsky notes that in the United States there has been a rapid change in public acceptance of the procedure, and that "many individuals who would oppose abortion for reasons of family limitation or convenience" would, nevertheless, accept abortion in cases of "a devastating disease such as Tay-Sachs or mongolism."[26]

AN ECHO NOT A CHOICE

In the August, 1976 issue of **MEDICAL OPINION,** Amitai Etzioni, Ph.D., author of **THE GENETIC FIX** examines the issue of amniocentesis in an article appropriately titled — "AMNIOCENTESIS: A PANDORA'S BOX".

In viewing the health risks of the technique, Etzioni states that "While a woman who has had amniocentesis and found her fetus to be abnormal does not HAVE to abort it, it usually makes no sense to undergo amniocentesis unless one is willing to act on its findings. **HENCE, ABORTION MUST BE CONSIDERED ONE OF THE GOALS OF AMNIOCENTESIS."**

Such a statement, of course, is in direct contradiction to the Williams conclusion in the **Homoletic and Pastoral Review** that abortion only may "occasionally intrude" to a "very minor extent" in early intrauterine diagnostic procedures to detect prenatal defects, as promoted by the National Foundation-March of Dimes.

Abortion — An Essential Ingredient

To summarize, then, we suggest that from a historical point of view, the Williams supposition that second trimester amniocentesis, for the purpose of determining prenatal defects, and selective abortion are tenuously joined by mere circumstance, cannot be validated.

Rather the historical facts backed by more current statements from **genetices** like Motulsky and Nadler substantiate the absolute necessity of selective abortion in relation to second trimester amniocentesis for the purpose of detecting fetal genetic abnormalities, hence the formula — LEGALIZED ABORTION + THE TECHNOLOGICAL FEASABILITY OF SECOND (AND IF NECESSARY THIRD) TRIMESTER ABORTIONS = AMNIOCENTESIS + DIAGNOSIS + ABORTION OF THE DEFECTIVE CHILD.

The ten year lag from 1958-1968 in bringing about a balance in the equation can be attributed to the existence of strong social and legal |sanctions **against** abortion in the early 60's within the medical profession and the community at large.

A brief recap of the evolution of permissive abortion laws in the United States might be helpful at this time.

CHAPTER VI

ABORTION LAWS IN THE UNITED STATES 1959-1973

THE LEGAL TURNING POINT[18]

The year 1959 marked the turning point in the movement toward relaxation of anti-abortion legislation in this country. In that year, The American Law Institute published a tentative draft of a revised statute on abortion to be included in the ALI's "Model Penal Code."

The provision was adopted with only minor revisions in May, 1962.

Among the justifications for abortion was the substantial risk that **"the child would be born with grave physical or mental defect."**

In June, 1967, The American Medical Association's House of Delegates passed a resolution containing a policy statement on therapeutic abortion. Among the provisions permitting abortion was the following —

> There is documented medical evidence that the infant may be born **with incapacitating physical deformity or mental deficiency —**

A similar provision was contained in the abortion statement of The American College of Obstetricians and Gynecologists in May, 1968, permitting abortion to prevent the birth of a child **"with grave physical deformities or mental retardation."**

By the end of the 1968 legislative session five states had passed new relaxed laws regarding abortion (Colorado, California, North Carolina, Maryland, and Georgia) each with varied provisions justifying abortion of defective children.

At this juncture the abortion movement was invigorated by the added support of the power American Civil Liberties Union, The American Public Health Association and Planned Parenthood-World Population, and the growth of well financed abortion-population control lobbies including the NARAL (National Association for Repeal of Abortion Laws) and internal bureaucratic government lobbies within the Department of Health Education and Welfare and The Agency for International Development.

By 1971, seventeen states and the District of Columbia had adopted abortion statutes, most of them patterned after the ALI Model Penal Code, 230.3.

In February, 1972, The American Bar Association approved the Uniform Abortion Act that had been drafted and approved the preceding August by the Conference of Commissioners on Uniform State Laws.

Section 1. (b) (2) (ii) provides for abortion where the child **"would be born with grave physical or mental defect."**

On January 22, 1973, The Supreme Court decision of Roe vs. Wade tore down the last vestiges of legal sanctions against **abortion at will.**

ABORTION AND THE DEFECTIVE CHILD Public Opinion Trends

Throughout this period, public opinion regarding abortion, specifically society's attitude toward the killing of defective children in the womb, was greatly influenced by the pronouncements of Ashley Montagu and Episcopalian moralist Joseph Fletcher. The "new morality" would justify a "new violence" — expedient and calculated — designed to yield the greatest net good.[19]

The degree of influence on public opinion towards the complete liberalized abortion law was no doubt magnified by the sympathy, horror, and anxiety engindered by the thalidomide tragedy of the 1960's which received world-wide attention in the case of Sherri Finkbine.

In a National Opinion Research Center public opinion survey conducted in December, 1965, based on a representative sample of 1484 adult Americans, 55% responded that they would approve of legal abortion if there is a strong chance of serious defect in the baby; 41% responded no; and 4% don't know.[20]

A later survey conducted by DeVries and Associates in March, 1975, for The National Committee for a Human Life Amendment, and based on a drawn National probability sample of 4.067 adult Americans reveals little change in public opinion on the issue of abortion and fetal defects.[21]

Asked, "Are you in favor of a law which permits a woman to have an abortion — if the woman had good reason to believe the child might be deformed," 55.5% responded in the affirmative.

NOTE: Breakdown by religion as follows:

Catholics	47.7%
Protestants	55.3
Jews	90.2

Interesting, however, and not without significance — 67.1% of the respondents in the DeVries poll stated they would **not** be in favor of abortion for a woman who is more than three months pregnant.[22] Given the fact that most abortions following amniocentesis and diagnosis of a defective child are carried out well past the 12 week stage, there appears to be a contradiction in responses which can be attributed to a lack of basic knowledge concerning the second trimester prerequisites associated with a successful amniocentesis procedure and accurate diagnostic response in the general population.

The "rationale" in the public mind in this matter was perhaps best summed up by Herbert Richardson, a Protestant theologian and professor at Harvard Divinity who has made the observation that we revere life more in ourselves and in those with whom we are closely identified than we do in

> "many of the weak, the mentally retarded, the physically disabled, the genetically defective . . . These all seem to lack some of the characteristics we feel are essential to ourselves . . ."[23]

Liberalization of Abortion Laws Parallels Second Trimester Amniocentesis Drive

Thus, the removal of legal sanctions against abortion in the United States, combined with widespread toleration, if not approval, of abortion by the general population for the elimination of defective children within the womb, historically paralleled the drive within the medical profession to legitimized amniocentesis for the purpose of selective abortion of the defective child.

NF-funded researcher Henry Nadler clearly summed up the relationship between liberalized abortion laws and the expansion of amniocentesis at the Ross Conference in 1972, covered in detail later in this report.

"I think we have come a long way . . . however, many problems will and have evolved, not the least of which are the legal and moral problems of the fetus and abortion. THERE ARE NO FETAL INDICATIONS FOR TERMINATION OF PREGNANCY IN ILLINOIS AND MANY OTHER STATES. OBVIOUSLY, LEGAL CHANGES WILL BE REQUIRED IF INTRAUTERINE DIAGNOSIS IS TO BE REALLY WIDELY UTILIZED IN THE FUTURE."* Obvious indeed!

(* from the Verbatim Transcript, Ross Conference, Ethical Dilemmas in Current Obstetrics and Newborn Care, May 13-15, 1972 P. 131.)

CHAPTER VII

INTRAUTERINE DIAGNOSIS AND SELECTIVE ABORTION NF-MOD ORIGINAL ARTICLE SERIES — 1970

One of the earliest sources of controversy between the Pro-Life Movement and March of Dimes was the National Foundation publication of the April, 1971 Original Article Series — **Intrauterine Diagnosis,**[27] containing the proceedings of the American Society of Human Genetics Symposium on "Intrauterine Diagnosis and Selective Abortion" held in Indianapolis on October 13-14, 1970.

In this second series of lectures and discussion on the ethical issues raised by new developments in the field of genetics, the participants are asked to address themselves to six specific questions raised in the technical, practical and ethical application of intrauterine diagnosis combined with selective abortion of the affected pre-born child. From the introductory remarks by James V. Neel, M.D. it is clear that neither traditional "therapeutic" uses and problems encountered in intrauterine diagnosis related to RH and DHS nor prenatal treatment of specific defects are at issue here.

If there is any question of the relationship between abortion and amniocentesis for the purpose of intrauterine diagnosis of genetic defects — this Series puts it to rest.

The following summaries of the **six papers and two commentaries** presented at the Symposium are provided for the reader's convenience. Editor's comments are in brackets:

★ **Indications for Amniocentesis in the Early Prenatal Detection of Genetic Disorders, Henry L. Nadler, M.D.**

Nadler lists known maternal and fetal risks associated with second trimester transabdominal amniocentesis, and examines the scope of problems associated with accurate intrauterine diagnosis. He states that amniocentesis should be performed by an experienced obstetrician who is "committed" to providing 'therapy', that is, abortion, if the results indicate an abnormality either by performing the abortion himself or in making a referral to an abortionist who will act upon the parents request.[28]

★ **Chromosomal Problems of Intrauterine Diagnosis, M. Neil Macintyre, Ph.D.**

Macintyre reminds the geneticist that while the fetus is "technically" the patient, practically speaking its the anxious parents who need understanding and support. The latter should be made fully aware that, regardless of amniocentesis finding, they cannot be GUARANTEED A PERFECT BABY. Parental consent and release of physician liability is a prerequisite to the amniocentesis procedure. Author notes the hazards of late abortions and warns that "undertaking a prenatal evaluation often means delaying what otherwise would have been an early therapeutic interruption."[29]

★ **Problems in the Use of the Cultured Amniotic Fluid Cells for Biomedical Diagnosis, John W. Littlefield, M.D.**

Author addresses himself to the technical problems involved in the use of cultured amniotic fluid cells for biochemical diagnosis, and stresses the absolute necessity of accuracy since "the decision to act" unlike most medical procedures "depends on the result of a single laboratory test."[30]

★ **Amniocentesis and Abortion: Methods and Risks, Fritz Fuchs, M.D.**

Author notes the difficulty in selecting the optional time for diagnostic amniocentesis because while amniocentesis is safer in the later stages of pregnancy, abortion is not, hence a "compromise" may be needed. [*ed.'s note — Dr. Fuch's conclusion is identical to this editor's remarks reached totally independent of the symposium readings.*] Further, he states his firm conviction that "amniocentesis should never be carried out unless one is prepared to act upon the results." Fuchs advises that *women* undertaking selective abortion should be advised of the complications of induced abortion including the possibility of secondary sterility.[31]

★ **Psychosocial Aspects of Selective Abortion,** E. James Lieberman, M.D. M.P.H.

The matter of informed consent is as essential to parenthood as it is to experimental procedures of amniocentesis and diagnosis of genetic defects. The author laments the rubber stamp role of the psychiatrist in abortion and states that we should "insist that the matter of abortion be a private decision between a woman and her physician." Late abortions are more traumatic — physiologically and psychologically.[32]

★ **Public Health and Long Term Genetic Implications of Intrauterine Diagnosis and Selective Abortion** Arno G. Motulsky, M.D., George R. Fraser, M.D., Ph.D. and Joseph Felsenstein

"Once established as safe, intrauterine diagnosis is likely to be made available to all such families after the birth of an affected child. The aim of such a program is THE IDENTIFICATION OF SUBSEQUENT CHILDREN AND THEIR SELECTIVE ABORTION." Paper includes table and statistics on number of abortions required to achieve the two-normal-child standard for heterozygote couples. Authors foresee the day when EVERY pregnancy will be monitored by amniocentesis to fulfill the two

child norm associated with population stabilization on the premise that most parents prefer to abort an affected fetus than care for a sick child "requires only but the most trivial treatment."[33]

★ **Discussion of Symposium Papers,** Orland J. Miller, M.D.

Elaborates on the experimental nature of amniocentesis and calls for increased research into the procedures long and short term maternal and fetal effects. Author suggests that there are other ways to prevent birth defects than by abortion but acknowledges that abortion will continue to play an expanded role in the elimination of the severely retarded. While he admits that many people regard abortion with abhorrence, he concludes that where a social climate exists for abortion simply on the basis of an "unwanted" pregnancy, the criteria for selective abortion might be broadened considerably . . .[34]

★ **Discussion of Symposium Papers,** Michael M. Kaback, M.D.

The author suggests that the "essence" of intrauterine diagnosis and selective abortion is to permit high risk couples the opportunity of having normal offspring. He notes that prostaglandin abortions and hysterotomies provide better fetal materials for post-abortal corroboration of initial diagnosis than saline abortions which destroys the unborn child's skin layers. Control fetal materials are readily available given the widespread increase in abortions for "psychosocial" indications.[34]

THE NATIONAL FOUNDATION REACTS

Shortly after the April, 1971 Publication of the Symposium Proceedings as an **Original Article Series,** the National Foundation found itself under fire.

Prolife critics publicly challenged the blatant anti-life orientation of the intrauterine diagnosis meeting and questioned the NF's role in including the "guide to extermination procedures of defectives via selective abortion" as part of its medical communication program on intrauterine changes.

The predictable reaction of the Foundation to prolife criticism especially on such a volatile issue as abortion followed a pattern with which our readers at this point should be well acquainted.

The **Public Relations** arm of the Foundation swung into high gear — the prolife community was misinformed — the Foundation didn't sponsor the Symposium it merely reported on the proceedings — the Symposium speakers didn't speak for the Foundation, and so forth. Within a few months, the National Foundation issued a position paper on Abortion and on amniocentesis.

Backing of the Foundation's explanation of the nature and intent of the Original Article Series reprint of the proceedings as primarily on academic venture in the scientific exchange of the technical aspects of amniocentesis was given by Rev. Bruce Williams and the U.S. Catholic Conference. Most prolife groups took a different view, however. [*Ed.' note — In the fall of 1973, at the request of Msgr. McHugh, the Foundation agreed* **NOT** *to reprint the publication, an action which in this editor's opinion served the Foundation's interests rather than prolife interests.*]

Separating Fact From Fiction

Let us begin with the fact that the National Foundation March of Dimes did **not** sponsor the Symposium. The Committee on Social Issues of The American Society of Human Genetics sponsored and conducted the proceedings.

However, **this** particular fact no way lessens the impact of **other** factors which link the National Foundation to the antilife orientation of the Symposium's participants whose views are expressed in this Original Articles Series.

Fact #1 — With the sole exception of Dr. Lieberman, who shortly after the October, 1970 Symposium became the psychiatric consultant to Preterm, one of Washington, D.C.'s most thriving aboritoriums, **all** speakers and commentators were and/or are associated with **institutions** conducting March of Dimes — National Foundation research or medical services programs.

The following tallies are based on a spot-check of NF research and medical grants to these institutions listed in the MOD **Facts** booklets from **1968 to 1976.** Travel expenses not included.

(Nadler)	Children's Mem. Hosp., Chicago	$378,000
(MacIntyre)	Case Western Reserve	170,000
(Littlefield)	Boston Hospital for Women, Harvard Medical School	
	Massachusetts General	80,000
	Also Ryan 5-year Grants ..... on birth defects and abortion	500,000
(Fuchs)	Cornell U. Medical College, N.Y. Hospital Rockefeller University	990,000
(Motulsky)	University of Washington, Seattle	330,000
(Miller)	Columbia University, New York	108,000
(Kaback)	John Hopkins U. (School of Medicine)	376,000

Fact #2 — A number of the Symposium speakers were and/or are recipients of National Foundation grants for research in the area of prenatal diagnosis and amniocentesis.

Henry Nadler, for example, has received substantial NF funding **every year** since 1968 and is recognized as a National Foundation authority on amniocentesis. To date he has received more than $300,000 in NF research grants.

Orlando Miller and **William Kabach** are other prominent recipients of NF funds totalling over $155,000. Both Nadler and Miller serve on the NF Research Advisory Committee. **Macintyre** has received a $10,000 grant.

Although there was no specific data available on direct research funding by the Foundation of **Little, Fuchs,** and **Motulsky** it is very probable that Foundation funds have reached these investigations through the medical services channels at their respective institutions listed above.

Given this additional information, it is obvious that the Original Article Series on the Intrauterine Diagnosis Symposium, **was in the eyes of the Foundation,** more than the mere technical recording of a group of strangers, with which the Foundation had no bond or relationship. Rather, the facts would suggest that, generally speaking, the participants' views were a clear reflection of the inner mind of the Foundation itself and of the scientific advisors, and that the Foundation implicitly approves of the killing of defective unborn, providing evidence of the defect was supported by an accurate intrauterine diagnosis.

To suggest otherwise is to pre-suppose that the Foundation is ignorant of the orientation and philosophies of its grant recipients — both institutions and individual. Yet if there is one thing this editor has gleened from months of research on the National Foundation it is, this — whatever the vices of the National Foundation — ignorance and sloth in the awarding of grants is not one of them.

Ah! But what about the possibility that this particular Symposium was an atypical happening. Can we condemn an organization solely on the basis of a **single** event? Should not other seminars and conferences be examined and compared with the 1970 Intrauterine Diagnosis Symposium?

CHAPTER VIII

GENETIC DECISION MAKING IN EARLY PREGNANCY NADLER AT THE ROSS CONFERENCE — 1972

The Conference on "Ethical Dilemmas in Current Obstetrics and Newborn Care" sponsored by Ross Laboratories, Columbus, Ohio, was conducted at the Indies Inn, Duck Key, Florida, May 13-15, 1972.[37]

Participants at the two-day conference represented professionals from a wide selection of medical fields as well as economics, law and medical ethics and theology including three National Foundation grant recipients.

Marvin Cornblath, MD	Conference Chairman, Specialists in Inborn Metabolic Errors
Stanley Graven, MD	1975-76 Grant to develop educational and consultant resources in perinatology for all Great Plains States.
Henry Nadler, MD	Specialist in Intrauterine Diagnosis

The issue of abortion in general, and "Selective Abortion" following intrauterine diagnosis is taken up by **Gordon Douglas,** MD., OB and GYN., NY University School of Medicine and **Henry Nadler,** MD of NW University Medical School, Chicago, respectively.

Dr. Douglas is upset that New York is becoming the Nation's abortion capital and suggests that other states be made to carry a portion of the patient load by standardizing abortion care and policing the profession with professional accreditation and peer review to reduce abortion excesses and abuses.

Nadler follows with an assortment of comments of the uses of amniocentesis in the prenatal diagnosis of a variety of metabolic disorders, not the least of which is the **admission that when he originally became involved in amniocentesis, he was quite naive,** believing one would not only have **the option for termination of pregnancy,** but might also have the **option for treatment.**

But the second "option" presented some basic problems —

> Even with accurate diagnosis of metabolic disorders in the second trimester, the physician is **already** behind in terms of prevention or reversal of the defect which may have already affected the fetus' critical organs, and, in certain disorders, it is impossible to distinguish between a fetus with the disease and a normal fetus who will be a carrier.[38] Nadler emphasized that ideally efficient, genetic decision making should be carried out **before** conception not after.

Later in a discussion of the universal applicability of amniocentesis combined with selective abortion, Nadler notes that mongolism might be eliminated in this way and billions of dollars would be saved. He also states that we can have an effective, accurate, reasonably priced technique if we are really prepared to recommend it on a nationwide scale.

Both Cornblath and Graven expressed considerable interest in the discussion on the effects of low birth weight, the respiratory distress syndrome and toxemia of pregnancy, and in the matter of economics and birth defects.

In one of the earlier sessions, Dr. Cornblath asks Dr. Richard E. Hatwick, Professor of Economics at Western Illinois University to comment on the impact of society of large numbers of critically ill infants — from an **economic** point of view.

Hatwick suggests the future possibility of a cost-benefit analysis in which the benefit of keeping a defective child alive would be measured by the cost of doing so. He concludes his presentation by suggesting that while some may find the economists' viewpoint repelling, its virtue stems from the fact that it recognizes what none of the other disciplines seems to recognize.

"Everything Has its Price."

To ignore the cost is to make a decision to use resources in areas which may not be deserving of them.

An interesting dialogue on selective abortion and infanticide is carried on between Rev. Joseph Fletcher and Dr. Henry Thiede, M.D. of the University of Mississippi School of Medicine.

Dr. Thiede asks Dr. Fletcher if from a philosophical standpoint, whether he believes it is better to destroy three normal fetuses for every affected one, as in the case of rubella contact of a pregnant woman, or whether it's better to let all four be born and **then** destroy the defective fetus.

Fletcher responses that it is better to abort **all** four pregnancies than endure the misery of **one** defective. The women are then free to try again.

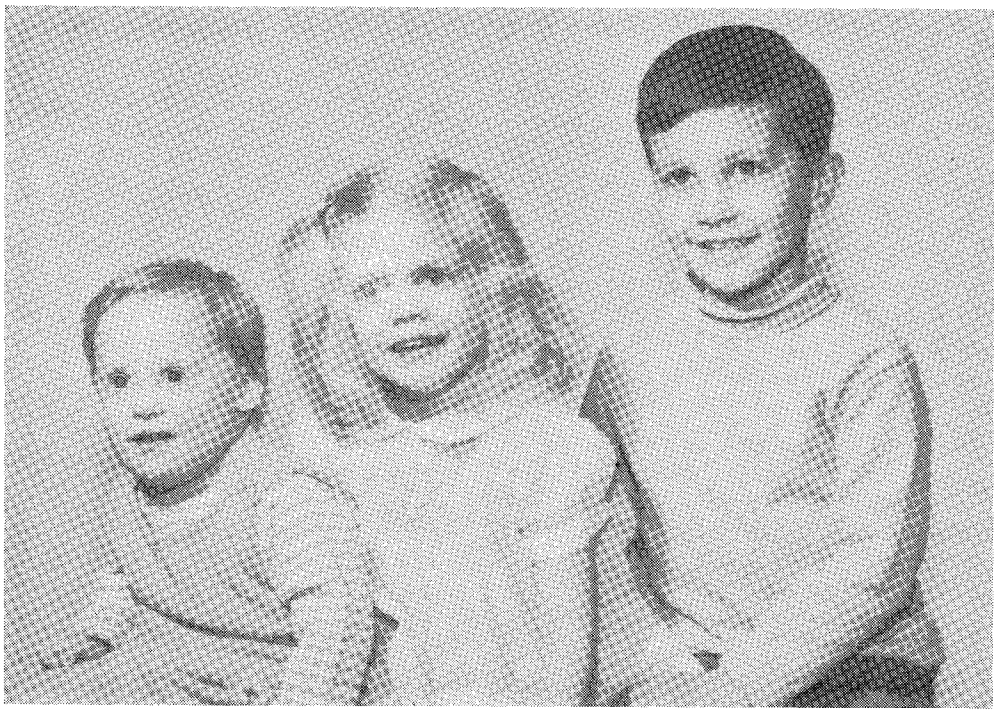
Dr. Thiede then asks if it is wrong to kill them in the delivery room if the newborn turn out to be a defective baby.

Fletcher responds that it is **not** wrong if a newborn shows a gross abnormality.

Later in a discussion on morality of decision making with Dr. Veatch of the Hastings Center in New York, Fletcher compares the "sanctity of life" ethic with the "quality of life" ethic and states that "NOBODY AT THIS MEETING, I GATHER HAS DEFENDED THE SANCTITY DOCTRINE, BUT IT IS STILL COMMONLY AND SINCERELY HELD BY MANY SEGMENTS OF THE PUBLIC."[39]

One of the most interesting comments on the role of the physician is made by Dr. Bradley E. Smith of Nashville, Tenn. who questions whether or not the doctor should be appointed and exploited as "society's executioner" in the matter of infanticide of a defective child at birth. He suggests that this can cause a mental strain on the physician as in the case of abortionists with similar difficulties posed by daily killings.

In conclusion, there appeared to be no disagreement among the Ross Conference participants, including the National Foundation grantees, as to the legitimacy of selective abortion following amniocentesis and the diagnosis of an affected child. The only discussion centered on how best to apply the principle, and this portion of the proceedings was lead by NF researcher Henry Nadler. The seemingly innordinate amount of discussion of the matter of infantcide of defective children indicated to this writer that even as early as the Spring of 1972, the value placed on human life was going down.



CHAPTER IX

THE HALL SURVEY

This study was conducted by (Mrs.) Selah Hall of Natchez, Mississippi in 1975, for the purpose of determining the attitudes of physicians who perform genetic services for the N.F., March of Dimes on selective abortion and related issues. Since this study was conducted as a private survey, the names of the physicians who responded to the survey, have been placed under seal.

The names and addresses of doctors performing genetic services for the NF-MOD was obtained from field Representative John Berger on January 13, 1975. On March 10, 1975, the following questionnaire was sent to the 89 physicians on the list —

Rule or Exception?

Due to the views expressed by National Foundation-funded physician and/or researchers at the ASHG Symposium in 1970 and the Ross Conference in 1972 and other similar symposiums and seminars on birth defects mentioned later in this report actually reflect the opinions of a **majority** of NF-MOD researchers and/or genetic counselors on the issue of intrauterine diagnosis and selective abortion today?

The results of the Hall Survey below indicate that the answer to this question is **YES.**

Dear Doctor:

In the midst of much public turmoil following what the American Medical Association calls an "outrageous" decision convicting Boston, Mass. Physician, Dr. Kenneth Edelin, of manslaughter, we are conducting a private poll that hopefully will reveal how this decision will affect physicians throughout the United States. We have selected a small number of doctors from each state, representing various fields of medical practice. Because this poll is not being conducted on a large scale, but rather on a select one, the importance of your reply cannot be over emphasized. We have enclosed a stamped, self-addressed envelope for your convenience. Thank you very much for your help.

Mrs. Selah Hall

CIRCLE ONE

1. Are you in agreement with the Suffork Superior Court decision regarding Dr. Kenneth Edelin?	YES	NO
2. In your opinion will this case affect a physician's willingness to perform an abortion?	YES	NO
3. Do you feel that the Doctor is being used as a scapegoat in the entire abortion controversy?	YES	NO
4. Do you think there is a need for legislation that would protect members of the Medical Profession in abortion cases?	YES	NO
5. Do you think abortions should be available on requests?	YES	NO
6. Do you feel that abortions should be limited to the first trimester of pregnancy unless the death of the mother is imminent?	YES	NO
7. If amniocentesis proves the fetus to be defective should an abortion be allowed regardless of the stage of pregnancy?	YES	NO
8. If you found a fetus to be defective following amniocentesis, would you advise termination of the pregnancy?	YES	NO
9. Is it your medical opinion that life begins at birth?	YES	NO
10. Is it your medical opinion that life begins at conception?	YES	NO

_____

(SIGNATURE)

RESULTS OF THE SURVEY

Sixty-six per cent (66%) of these questionnaires have been returned or 66% of these 89 doctors have responded in some way to this survey.

Sixteen of the sixty returned questionnaires were not filled out for various reasons:

One doctor was deceased

Four doctors had moved and left no forwarding address

Three said they were not Doctors of Medicine so didn't complete the survey but they did sign the form

Eight doctors returned the questionnaire without filling it out because they did not know the purpose of the survey

Forty-four (44) of the questionnaires are completed and all but four of these have the signature of the doctor to which it was sent.

The physicians that did complete the questionnaire did not always answer all the questions, but usually they did give their reasons for not doing so. Some of their excuses ranged from the questions being irrelevant, improperly stated, and/or not having formed a definite opinion on the issue.

Forty-four (44) of the sixty questionnaires that were returned contain comments that the doctors themselves wrote on them. Some of these comments are:

Question 8	1. "I would perform" (the abortion) 2. (I would advise abortion) "as a part of complete counseling" 3. "I would offer it" (abortion)
Question 6	1. "That would be the end of pre-natal diagnosis" (if abortions were limited)
Question 3	1. "The doctor was secondary to the political aspects of the case"
Questions 9&10	1. "Meaningless" (when life begins) 2. "Not a medical problem" (beginning of a new unique human life) 3. "Irrelevant" (when life begins)

One doctor asked to have the final results of this survey sent to his residence and included his home phone number and address.

Oddly enough, in most instances those doctors that answered "yes" to questions 5, 7, and 8, were the same doctors that answered "yes" to question 10. Judging from this and some of the comments it would seem that the question of when human life begins has little or no significance to these physicians if that human life is defective and often even if it is not defective.

BREAKDOWN OF QUESTIONS ON SURVEY

Question 1. Ninety-five per cent (95%) of the forty-two doctors responding to this question said they were **not** in agreement with the Court decision regarding Dr. Edelin.

Question 2. One hundred per cent (100%) of the 43 responding doctors felt that the Edelin decision would affect a physician's willingness to perform abortions.

Question 3. Seventy-nine per cent (79%) of the 39 responding doctors felt that the physician is being used as the scapegoat in the abortion controversy.

Question 4. Seventy-nine per cent (79%) of the 39 responding doctors felt there's a need for laws to protect them.

Question 5. Eighty-eight per cent (88%) of the 44 responding doctors think that abortion should be available on request.

Question 6. Eighty-five per cent (85%) of the 42 responding doctors do **not** feel that abortions should be limited to the first trimester of pregnancy even if an abortion would be allowed later if the death of the mother was imminent.

Question 7. Seventy-one per cent (71%) of the 42 responding doctors said that if the fetus proved to be defective following amniocentesis that an abortion should be allowed regardless of the stage of pregnancy.

Question 8. Sixty-eight per cent (68%) of the 41 responding doctors said they **would advise** termination of the pregnancy if amniocentesis proved the fetus to be defective.

Question 9. Sixty-four per cent (64%) of the 34 responding doctors hold the opinion that life does **not** begin at birth.

Question 10. Forty-five per cent (45%) of the 33 responding doctors hold the opinion that life begins at conception.

All of these doctors are providing genetic services for the National Foundation-March of Dimes.

[*Editor's Comments — The results of the Hall Survey appear to correspond to this writer's conclusion about the strong relationship between abortion to defective children and second trimester abortion, and the questionable validity of the National Foundation's ability to retain a position on the "neutrality" on abortion. The survey reveals that in* **practical application** *as opposed to public relations pronouncements it is neither applicable nor enforceable.*]

The Patient As An Independent Consumer

The Foundation has stated that a decision to terminate a pregnancy should **not** be directed by **the** scientist, physician, or other persons providing genetic services. The fallacy of this position is best illustrated, by implication, by Dr. Mildred Stahlman, Chairman of the 1972 Ross Conference who candidly commented on the matter of informed consent and the influence of the attending physician thusly —

> I would like to address myself to the problem of informed consent. I believe, as a physician who has had prior contact with the family, that I can persuade 99% of parents to my way of thinking if I really work at it, *even if I am 100% wrong.* If I tell them in such a way that I appear concerned and that I am knowledgeable and that I have their interests at heart and the interest of their fetus or their new born baby, there is no question in my mind but what they will let me "cut off the infant's head." I think informed consent is an absolute farce legalistically, morally, ethically — any point of view you want to talk about. THE INFORMATION IS WHAT I WANT IT TO BE.[40]

CONCLUSION OF PART I.

The Hall Survey concludes this segment of the U.S. Coalition for Life's Special Report on the National Foundation-March of Dimes.

In our second and concluding segments of this report we will examine in depth specific genetic counseling and genetic research programs of the National Foundation as well as the safety, reliability and other factors related to amniocentesis.

Additionally, we will examine the following topics —

Fetal Experimentation and the NF-MOD

Amniocentesis — Risks vs Benefits

Down's Syndrome and Selective Abortion

Tays-Sachs Disease and Mass Screening

Federal Programs of Intrauterine Diagnosis for Prenatal Defects

NF-MOD Teen Programs

New Techniques of Intrauterine Diagnoses

Selective Abortion —
Moral and Ethical Considerations

The Ryan Grant —
Abortion and Birth Defects

Amniocentesis and Sex Selection

The Salk Institute —
Its Programs, Policy, and Philosophy

Life Devoid of Value
The Physician Turned Technic

PRO-LIFE ALTERNATIVES to the
National Foundation-March of Dimes Program

LORD, help us to remember that the physically and mentally ill were also created by you. Handicapped as they are, they are a challenge to our love of neighbor and to our readiness to sacrifice even if it means some suffering.

Let us remember the mothers whose children have been born sick or are the victims of hereditary defects. All their life long they must depend upon the care and assistance of their fellow-men.

We cannot allow them to be murdered just because some misguided person thinks that their life is not worth living.

LORD, do not permit the acceptance of what mistakenly called euthanasia, or mercy-killing. Make us ever ready to extend our loving care to the elderly and to the physically and mentally handicapped.

(translated from **Kruezewg der Ungeborenen** — The Way of the Cross for the Right to Life — originally published in Regensburg, Germany.)

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