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(MRS.) JUDIE BROWN
PRESIDENT

OFFICES: (703) 659-4171
(METRO DC #690-2049)

THE VALUE OF LIFE COMMITTEE, INC.
637 CAMBRIDGE STREET
BRIGHTON, MASS. 02135
TELEPHONE: (617) 787-4400

September 9, 1983

PLEASE, PLEASE, THIS IS VERY IMPORTANT MATERIAL !!

"Let merciful caring not mercy killing be our answer to their needs."

Richard and Leonie Watson, 9/2/83

MEMORANDUM TO: Certain Friends of the Unborn and Handicapped Newborn

FROM: Joseph R. Stanton, M.D.

I just received from Dr. Rick Watson in California:

(1) His and his wife's beautiful and meaningful testimony in support of Infant Doe Regulations. To one who has seen Rick Watson lovingly care for their little special son, this beautiful, from the soul, witness is a Christian manifesto on the meaning of acceptance and love.

(2) Canadian Psychiatric Association Position Paper, May, 1978, I had not previously seen. It is an important document.

(3) The March 13, 1983 Canadian decision in re Stephen Dawson. Must reading!

Additionally, I enclose Dr. Strain's NEJM paper of Aug. 18, 1983. Strain is president of American Academy of Pediatrics, the successful enjoiner, courtesy of Judge Gesell, of the original Baby Doe Regulations.

This material should be a valuable resource in defense of present Infant Doe Regulations.

Sincerely,

Joseph Stanton

Joseph R. Stanton, M.D.

JRS/mry
Enclosure

RICHARD A. WATSON, M.D., F.A.C.S.
345-A ARGUELLO BOULEVARD
SAN FRANCISCO, CALIFORNIA 94129

(415) 561-2556

September 2, 1983

TESTIMONY IN SUPPORT OF PROPOSED RULES FOR NON-DISCRIMINATION ON THE BASIS OF HANDICAP RELATING TO HEALTH CARE FOR HANDICAPPED INFANTS
(45 CFR Part 84)

The Department of Health and Human Services has recently proposed regulations to facilitate reporting and governmental intervention in cases of deliberate neglect against handicapped infants. We understand that these proposed rules have raised serious concern on the part both of families and of physicians.

As the mother and father of seven children, we very much appreciate the concern of those parents who resent and mistrust further governmental intrusion into the family, particularly in this sensitive area of moral decision-making. Still, a limit must ultimately be set, even to the sovereignty of the family. A recent decision from the Supreme Court of British Columbia rules:

> I am satisfied that the laws of our society are structured to preserve, protect and maintain human life and that in the exercise of its inherent jurisdiction, this court could not sanction the termination of a life except for the most coercive reasons. The presumption must be in favor of life...I do not think that it lies within the prerogative of any parent or of this court to look down upon a disadvantaged person and judge the quality of that person's life to be so low as not to be deserving of continuance. *

Second, as physicians, we both very much appreciate the concern of those in the medical profession who oppose further governmental inroads into the confidentiality of the doctor-patient relationship, particularly with regard to difficult therapeutic decisions. Still again, there must ultimately be a limit set. The Canadian Psychiatric Association, in its "Position Paper on Withholding Treatment", makes the following observation:

> We recognize that many have advanced arguments for the withholding of treatment which are cogent both to themselves and to others. But we must ask, "Is this the task of the physician?"
>
> The aspiration of our profession has always been to spare no effort in our attempt to prevent illness, to promote healing, to reduce suffering and to save life.
>
> The time-honored ethic of medicine, that a live patient is better off than a dead one and that a well person is better off than a sick one, is a simple ethic ...but it has been an effective one.
>
> Medicine is the healing profession. Medicine is the treating profession. Medicine has earned its honored position not only by appearing to take the patient's side, but by taking the patient's side in point of fact. We have become trusted because we deserve to be trusted.
>
> Medicine betrays its identity, and fails in its public trust, when it finds any reason to dicker with death--when it accepts the death of an individual as a means of solving the problems of either the family or of society.
>
> In this context using terms such as "ordinary means of treatment" and "extraordinary means of treatment" is irrelevant. These concepts are outside that range of attitudes which the physician can adopt without running the risk of becoming an agent of harm to his patient.
>
> The physician must be on the side of his patient. This is his traditional role, this is his moral role, and this is his only role. *

Finally, as the parents of an eight-year-old boy with Down's Syndrome, who suffers from marked retardation and a severe cardio-pulmonary condition, we do appreciate both the deep anguish and the countless joys that derive from caring for and caring about a severely handicapped child. Yet, when Peter was newly born, how easy it could have been in the shock of first realizing his weakness, to have allowed one terrified moment of "No!" to slam the door on this lifetime of "Yes"es. There is no limit set on the strength, the growth and the fulfillment that his love continues to bring us every day. For his sake and for the sake of all the handicapped newborn, it is urgent that safeguards be enacted. Let merciful caring, not mercy-killing, be our answer to their needs.

Respectfully,

Leonie S. Watson, M.D.

Leonie S. Watson, M.D.

Richard A. Watson, M.D.

* These two reports from Canada lend valuable insights into the issue at hand. We enclose complete copies of each in the hope that you will give them both your full attention.

new telephone number: (415) 921-4636

ÇANADIAN PSYCHIATRIC ASSOCIATION • ASSOCIATION DES PSYCHIATRES DU CANADA
SUITE 103, 225 LISGAR STREET • OTTAWA K2P 0C6, CANADA • APPARTEMENT 103, 225 RUE LISGAR

THE CANADIAN PSYCHIATRIC ASSOCIATION

POSITION PAPER

ON WITHHOLDING TREATMENT

DISPLAY ONLY

ON WITHHOLDING TREATMENT

A Working Paper

for

The Professional Standards and Practice Council

of

The Canadian Psychiatric Association

prepared by
M. N. Beck, M.D.
May 1978

This paper will offer a brief overview of the argument against the practice of withholding medical treatment from newborn retarded children.

The ethical issues stemming from this practice are most pointedly drawn by withholding repair of atresia of the duodenum in infants with Down's syndrome - "an easily correctible lesion" (1).

Similar principles are involved, but with more complex factors to be evaluated in terms of diagnosis and prognosis in cases of meningomyelocoele.

The Present Scene

In considering this practice we do not discuss a theoretical issue, but we deal with facts in clinical medicine in Canada today.

50 children with Down's syndrome and duodenal atresia were attended at the Sick Children's Hospital in Toronto over twenty years, of these, 27 were allowed to die (2).

This increasingly common act in medical practice is being vigorously promoted by able and influential advocates within our profession and within our society at large.

Withholding treatment from mongoloid children was first openly advocated as a valid option to Canadian medicine by Frank Guttman, M.D., F.R.C.S. in his article "On Withholding Treatment" in the Canadian Medical Association Journal of September 21, 1974 (1). Since then this topic has been subject to much discussion in the correspondence section of this Journal (3, 4).

Cooperman discussing meningomyelocoele in an editorial in the C.M.A.J. favors withholding treatment (5). In the New England Journal of Medicine April 1976 John Lachs, Ph.D discussing the same topic commented, "the system if rightly conceived would not condone murder, for those humanely put to death would not be human beings, ly human forms" (6). In this he follows the philosophical position ken by the well known American theologian Joseph Fletcher (7, 8).

This practice has found professional support from such stinguished Canadian physicians as Dr. Clinton Stephens, Chief of neral Surgery, Hospital for Sick Children, Toronto (9) and Dr. Colin rguson, Surgeon in Chief, Children's Hospital, Winnipeg (10) in ir statements in the public media.

Individual instances of this practice have received wide erage in the Canadian press (11, 12) and such reputable newspapers as Montreal Gazette have given this practice editorial endorsement.

Battles both to permit and to enjoin this practice have n fought in Canadian and American Courts of Law (13, 14, 15).

The church is also involved. Withholding treatment was quently advocated in the report of the Anglican Task Force on Human e prepared for consideration by the National Synod of the Anglican rch in Canada in August of 1977. This Task Force was headed by Lawrence Whytehead, a surgeon from Winnipeg, and had in its bership others from the medical and nursing professions. The ret of this Task Force was just as eloquently condemned by the tements issued in response to it by the Canadian Association for Mentally Retarded and other groups (16, 17).

Professional Identity of the Physician

We recognize that many have advanced arguments for the hholding of treatment which are cogent both to themselves and to ers. But we must ask, "is this the task of the physician?"

The aspiration of our profession has always been to re no effort in our attempt to prevent illness, to promote healing, reduce suffering and to save life.

The time-honored ethic of medicine, that a live patient is better off than a dead one and that a well person is better off than a sick one, is a simple ethic .... but it has been an effective one.

Medicine is the healing profession. Medicine is the treating profession. Medicine has earned its honored position not only by appearing to take the patient's side, but by taking the patient's side in point of fact. We have become trusted because we deserve to be trusted.

Medicine betrays its identity, and fails in its public trust, when it finds any reason to dicker with death - when it accepts the death of an individual as a means of solving the problems of either the family or of society.

In this context using terms such as "ordinary means of treatment" and "extraordinary means of treatment" is irrelevant. These concepts are outside that range of attitudes which the physician can adopt without running the risk of becoming an agent of harm to his patient.

The physician must be on the side of his patient. This is his traditional role, this is his moral role, and this is his only role.

The Clinical Reality

Psychiatrists have had the priviledge to become those physicians most closely acquainted with that warm hearted, effervescent, usually happy, and warmly responsive group of people our society usually calls "mongoloids." They have taught us much about the appreciation of life, and they have shown us by their example the virtue and the value of an open human spirit.

We have also become familiar in our practices with the burden that can be placed on the family by retarded children. However; experienced child psychiatrists will agree that the person afflicted with Childhood Schizophrenia, a disease more difficult to diagnose than Down's syndrome, causes much more personal distress to the patient and suffering in his family (to say nothing of frustration and despair to medical people) than do mongoloid children or children with meningomyelocoele.

We would not decry all suffering, confuse it with illness or use it to justify less than the best of medical care. Suffering, like death, is a part of life. While it is terrible to bring it about unnecessarily, people often act nobly in accepting it, and through suffering their life has been enriched (18).

The members of this Association, parents, family members and others who have lived and worked closely with the retarded and their families also know the power of retarded children to strengthen and to revitalize their family units.

Whether the family unit becomes stronger or weaker depends upon those with whom they interact, as well as upon the retarded persons themselves. Neither human frailty, nor the ability to inflict suffering on others, is limited to intellectually subnormal individuals.

The Psychiatric Scene Today

During the professional lifetimes of many of our members, we have participated in a remarkable, even astounding, series of advances in the treatment of disorders of the mind. We ought to no longer assume that disorders of the mind are incurable, irreversible or always attended by much suffering.

In the thirties we saw a substantial reduction in our mental hospital population by the successful treatment of the psychotic illnesses caused by nutritional deficiencies.

In the forties we took part in the virtual elimination of General Paresis of the Insane. Till then patients with this disorder had occupied 5% of mental hospital beds.

In the forties and fifties we have seen the scourge of Manic-Depressive Psychosis become a highly treatable illness; first by the use of electro-shock therapy, then by the use of anti-depressant drugs, and more recently by the use of the simple salt lithium carbonate.

In the mid fifties the introduction of the major tranquilizers enabled us to obtain dramatic symptomatic improvement in the large number of our patients who suffer from schizophrenia.

During these same decades refinements of the techniques of psychotherapy brought about significant progress in the treatment of the psychoneuroses.

During the sixties we observed with delight the normal development of children born with phenylketoneuria and other inborn errors of metabolism which until then had invariably produced severe mental retardation. This advance was made possible by special diets. In the same decade because of improved surgical techniques we have watched large numbers of children growing up with intelligence in the normal range who would otherwise have been profoundly retarded because of hydrocephalus.

Of all times in history, this is not the one in which to be pessimistic about the possibility that still more major breakthroughs will be made in the treatment of mental disorders. The reasonable man now has good cause to anticipate the development of a biological method of treatment to correct or to modify the effect of the genetic defect which causes Down's syndr

These are not the times in which we should be either starting or expanding the practice of letting mongoloid infants die.

We also face this issue of withholding treatment at the very point in Canadian history when the efforts of voluntary associations like the Canadian Association for the Mentally Retarded and The Canadian Mental Health Association, along with the efforts of professional groups such as The Canadian Medical Association, The Canadian Paediatric Association and our own Association have succeeded in diminishing that oppressive social stigma which had been the lot of persons suffering from retardation and other handicaps. Working together we have also demonstrated that with good family care and with adequate education, rehabilitation and therapy, that retarded people make an invaluable contribution to the depth and the texture of the matrix of our society.

"Conventional wisdom" can no longer adequately serve as the prognostic guide in any disorder of the mind. Prognosis in mental diseases involves the assessment of a complex interrelated set of genetic, biochemical, psychological, social and cultural factors in a world where new and major therapeutic breakthroughs in all these areas of study has become a regular occurrence.

The Philosophical Dilemma

The distinguished jurist of the State of Maine who found against withholding surgery in a brain damaged infant commented that, "the doctor's qualitative evaluation of the value of the life to be preserved is not legally within the scope of his expertise" (16). We agree. We would also accept as valid the parallel statement, "that philosophy has no special competence in moral decision making."

We are aware that the heat involved in this issue besetting medicine arises from confrontation between persons who advocate a system of ethics centered on the "sanctity of life" on the one hand, and persons who hold a system of ethics centered on "the quality of life" on the other hand.

These value orientations weigh upon physicians in a particularly unique way. Our moral judgements, whether they be right or wrong, can exert undue influence on others because of our social role; and also because we are interacting with the members of the infant's family at a time when their lives are in acute crisis.

Sweating from the heat of this philosophical and ethical confrontation, we find helpful direction from our awareness that there is a profound distinction between maintaining life and prolonging death. Physicians can determine when death is inevitable with reasonable certainty. Merely postponing the time of death has never been accepted as good medical practice.

Our profession had incorporated this principle into its definition of good medical care long before the much heralded advances in bio-medical technology of the last few decades - which advances are now erroneously proposed as the reason for our having to rethink our ethics on the issue being discussed in this paper.

We recognize the logic in the sentiment expressed by Freeman that it is time that society, and medicine, stopped perpetuating the fiction that withholding treatment from those who will thereby continue to live, is ethically different from terminating life.

We are also uncomfortably aware that it is all too easy to slip into "doublethink" in this complex area of moral decision making as we exercise our medical responsibility. Our minds can easily move from the goodly desire (held we hope by all physicians) for a rich, full and satisfying life for everyone; to the recognition that, as we perceive their present situation to be, these children may never enjoy such a life; to the latter becoming the reason for our countenancing or even inducing their death.

The role of medicine is to help make the quality of life the best possible for all; rather than to cut short the life of humans with various defects - regardless of the degree or type of their deficiency.

Finally, we recognize that the protection of, and provision for, the welfare of the handicapped is a highly significant yardstick of the quality of our civilization; and that as stated by Dr. David J. Roy, "when we stand before a broken child and ask what we should do or avoid doing, we also stand before ourselves and before the civilization we both reflect and shape."

<u>Recommendations</u>

We therefore recommend:

1. That the Canadian Psychiatric Association oppose the practice of physicians withholding treatment of any kind, from retarded persons, which would not be withheld from persons with normal intelligence.

2. That physicians constantly strive to preserve life. And that when the medical reality of merely prolonging the process of dying is not involved, that withholding treatment be considered a legal and not a medical act; and that it be carried out - if at all - only under court order.

3. That the Canadian Psychiatric Association recognizes that the parents involved in these very difficult decisions need sympathetic and understanding assistance from experts in medicine, law, ethics, and clerical counselling; and that in a unique way it is the responsibility of physicians, and especially of psychiatrists,

4. That the Canadian Psychiatric Association advise the Canadian Medical Association and relevant specialty associations of our position on this matter.

) Guttman, F.M.; On Withholding Treatment, C.M.A.J.: 111, 520, 1974

) Girvan, D.P. and Stephens C.A.; Congenital Intrinsic Duodenal Obstruction, A Twenty Year Review of Its Surgical Management and Consequences; Journal of Paediatric Surgery, 9: 837; 1974

) DeVeber, L.L.; On Withholding Treatment; C.M.A.J. 111, 1183, 1974

) Baunemann, H; Life Devoid of Value; C.M.A.J. 115, 1086, 1976

) Cooperman, E.M.; Meningomyelocoele: To Treat or Not to Treat; C.M.A.J.: 116, 1339, 1977

) Lachs J.; Human Treatment and The Treatment of Humans; N. Engl. J. Med., 294, 839, 1976

) Fletcher J.; Ethical Aspects of Genetic Controls: Designed Genetic Changes in Man; N. Engl. J. of Med. 285, 776, 1971

) Fletcher J.; The Right To Die: A Theologian Comments; The Atlantic Monthly, 221, (April 1968) 63-64.

) a) Fletcher J.; Indicators of Humanhood: A Tentative Profile of Man; The Hastings Center Report; 2, 1, 1972

) Toronto Globe and Mail; Brain Damaged Baby Denied Operation That May Have Averted Starvation Death; October 8, 1974

0) Toronto Star; Doctor Wants Life or Death Guidelines for Mongoloid Children: July 19, 1972

1) Montreal Gazette; "Useless" Baby Allowed to Die; October 5, 1974

2) Edmonton Journal; Stop Letting Helpless Babies Die; November 11, 1974

3) Toronto Star; Christmas Eve Court Saves Baby; January 21, 1977

) Family Court Hearing; Judge M. Geness; London, Ontario December 24, 1976

5) Maine Medical Center Houle - Civ. Act No. 74-145. Superior Court, Cumberland, Maine. (February 14, 1974)

6) The Toronto Globe & Mail; Severely Retarded Babies Should be Killed, Anglican Report Suggests; July 27, 1977

7) Report of The Task Force on Human Life of the Anglican Church of Canada to General Synod; Editors, Whytehead L.and Clicdwick F; Considerations Concerning the Transit from Life to Death; Winnipeg, Man., May 1977

3) Weber, L.J.; Who Shall Life; The Dilemma of Severely Handicapped Children ar Its Meaning for Other Moral Issues;

VANCOUVER
MAR 18 1983
REGISTRY

IN THE SUPREME COURT OF BRITISH COLUMBIA

IN THE MATTER OF STEPHEN DAWSON AND IN THE MATTER OF A JUDICIAL REVIEW OF A DECISION OF HER HONOUR JUDGE BYRNE, A JUDGE OF THE PROVINCIAL COURT OF BRITISH COLUMBIA, RESPECTING A MALE INFANT BORN MARCH 29TH, 1976, (STEPHEN DAWSON)

NO. C831628
Vancouver Registry

BETWEEN:

THE SUPERINTENDENT OF FAMILY AND CHILD SERVICE

PETITIONER

AND:

ROBERT DAWSON and SHARON DAWSON

RESPONDENTS

NO. 830797
Vancouver Registry

BETWEEN:

PHILIP J. RUSSELL, British Columbia Association for the Mentally Retarded, the Public Trustee for the Province of British Columbia and STEPHEN DAWSON by his Guardian ad Litem, the Public Trustee for the Province of British Columbia

PETITIONERS

AND:

THE SUPERINTENDENT OF FAMILY AND CHILD SERVICE FOR THE PROVINCE OF BRITISH COLUMBIA ROBERT DAWSON AND SHARON DAWSON

RESPONDENTS

ORAL REASONS FOR JUDGMENT

OF THE HONOURABLE

MR. JUSTICE McKENZIE

COUNSEL:

J.J. Threlfall, Esq.	for the Superintendent of Family and anc Child Service
Ms. L.P. Stewart	for Robert Dawson and Sharon Dawson
W.E. Stilling, Esq.	As Family Advocate
David H. Vickers, Esq.	For Philip J. Russell, British Columbia Association for the Mentally Retarded and The Public Trustee;

NOTE: Ms. Stewart took ill and was replaced for argument only by:

J.E. Bothell, Esq. and
Ms. Elizabeth Kelly.

The subject of these proceedings is a severely retarded boy approaching 7 years, who shortly after birth suffered profound brain damage through meningitis which inflamed the lining of his brain and left him with no control over his faculties, limbs or bodily functions. At the age of 5 months life-support surgery was performed by implanting a shunt which is a plastic tube which drains excess cerebro-spinal fluid from head to another body cavity from which it is expelled or absorbed.

As perceived by his parents the boy is legally blind, with atrophied optic nerves, partly deaf, incontinent, cannot hold a spoon to feed himself, cannot stand, walk, talk or hold objects. They say that he has no method of communicating with his environment and think he is in pain. The sounds he makes are too soft to be heard from any distance. He is subject to seizures despite anti-convulsant medication. He is restrained by splints which are bandages on his arms to keep his elbows straight so that he cannot chew on his hands and roughly handle his face. Staff carry him from bed to wheelchair, which has a molded "insert" to ensure he is held securely and he is belted in with a hip belt.

This description applies to his condition as it existed when he was a patient in Sunnyhill Hospital before the shunt stopped operating. About 6 weeks ago a blockage in the shunt was detected and the parents gave their consent to remedial surgery but, after a day's reflection, withdrew their consent on the ground that the boy should be allowed to die with dignity rather than continue to endure a life of suffering. They continue to maintain that position.

Because of the parent's refusal the Superintendent of Family and Child Service, acting under the Act which creates his office (S.B.C. 1980 C.11) and mindful of the provisions (s.2) which makes the safety and well-being of a child the paramount consideration in administering and interpreting the Act, considered this child "in need of protection" and acted under s.9 to apprehend him. The quoted words, as defined in s.1, have several meanings, in relation to a child, including that he is "deprived of necessary medical attention".

Following apprehension, the Superintendent, conforming with s.11, presented a written report to the Provincial Court of British Columbia and asked for an order that the custody of the child be retained by him pending a hearing to determine whether the child was in need of protection. Following 5 days of hearing and a weekend's contemplation and writing, the Provincial Court Judge read in open court a 29 page oral judgment on 14 March 1983 which ordered the Superintendent to return the child to his parents' custody. The Judge identified the issue as:

> Who may exercise an incompetent's right to refuse life sustaining treatment if no directive exists and the incompetent is unable to do so? (P.24 of her reasons)

(Quoting from In the Matter of Bertha Collyer, S.Ct. Wash., March 10, 1983.)

The Judge appears to have held that this right belongs in the family, in consultation with their medical advisors. Where treatment would serve "only to prolong a life inflicted with an incurable condition" (p.25) rather than cure or improve the patient's condition, the interest of the state in the preservation of life is overriden by the wishes of the people whose duty it is to make the decision.

Adopting the distinction between treatment that "cures" and treatment that simply "prolongs life where there is no hope of recovery" the Judge found that the shunt revision fell into the latter category.

The Judge found that the shunt revision in Stephen's case constituted an "extraordinary surgical intervention", and not "necessary medical attention". Since Stephen was therefore not deprived of "necessary medical attention" there was no basis for the belief that Stephen was not a "well-cared for and loved child", and she concluded that she should order that he be returned to his parents under s.11(2)(b) of the Family and Child Service Act. S.11 sets out the procedure for review of the Superintendent's decision to apprehend a child pending a hearing on the question of whether the child is in need of protection. The Judge also held that the shunt revision would constitute a violation of Stephen's right not to be subjected to cruel and unusual treatment under s.12 of the Canadian Charter of Rights and Freedoms.

I think that the Superintendent's petition is accurate in contending that the learned Judge:

1) Held that a life saving operation does not amount to necessary medical attention as defined in s.1.

2) Did not consider as paramount the safety and well-being of the child as required in s.2.

3) Held that the shunt revision constituted cruel and unusual punishment under s.12 of the Canadian Charter of Rights and Freedoms, Constitution Act, 1982.

4) Did not consider s. 7 of the Charter.

By referring to the proceedings in Provincial Court and to the disposition of those proceedings I have done so for narrative reasons only because, as I conceive it, the <u>parens patriae</u> jurisdiction of the Supreme Court in this matter takes precedence over the proceedings in Provincial Court and allows this court to act as if the matter came before it in the first instance. Confirmation of this view is contained in s.21 of the Act.

> Nothing in this Act limits the inherent jurisdiction of the Crown, through the Supreme Court, over infants, as parens patriae, and the Supreme Court may rescind a permanent order where it is satisfied that to do so is conducive to a child's best interest and welfare.

Time does not permit me to expand on this aspect or on other important aspects of this case, such as the standing of Philip J. Russell, President of the British Columbia Association for the Mentally Retarded or of the Public Trustee for the Province of British Columbia, who come before the court as petitioners in a petition separate from that instituted by the Superintendent. Because of the urgency of the situation I will act on the assumption, which I believe to be sound, that the Superintendent unquestionably has standing and that the other petitioners are duplicating his arguments, or, at least, are duplicating his argument that this court should exercise its inherent jurisdiction as parens patriae and authorize medical and surgical treatment as required by the boy. Indeed, the parents seek the invocation of the same jurisdiction but ask that it be applied to support their position.

I propose to examine the matter from the parens patriae point of view as expressed by Lord Eldon, L.C. in Wellesley v. Duke of Beaufort (1827) 2 Russ. 1 at 18, affirmed 2 Bligh N.S. 124, 4 E.R. 1078 by the House of Lords:

> It has always been the principle of this court, not to risk the incurring of damage to children which it cannot repair, but rather to prevent the damage being done.

And at p. 20:

> . . . more especially, whether it belong to the King, as parens patriae, having the case of those who are not able to take care of themselves, and is founded on the obvious necessity that the law should place somewhere the care of individuals who cannot take care of themselves, particularly in cases where it is clear that some care should be thrown around them.

The parents' attitude is basically one of despair. They see themselves as loving and concerned parents who see no hope for this child and no prospect of relief of his suffering but only the dismal prospect of a long, painful progress toward the end of a meaningless life. They believe that without the shunt he will soon die. They want him to be allowed to die in peace. They think they know him best and they distrust and reject the opinions of the people who have been looking after him in hospital. They think these people are "emotionally involved" and are doing as they are told, or saying what they are told to say, by the Superintendent. These people and their evidence is here briefly described:

1) Dr. Hill is a pediatric specialist who is Medical Director of Sunnyhill Hospital which specializes in the long term care and rehabilitation of children suffering from chronic handicaps. He has been aware of Stephen since 1978 upon his first admission to Sunnyhill and particularly aware since his second admission in January 1982. During an interval in 1979 Stephen was in a foster home. To him the boy appears as extremely

retarded with no control over his faculties and limbs. On 14 February 1983 he observed the apparent shunt defect. Since 14 February he has noted marked deterioration owing to increased intercranial pressure. In his opinion more delay will cause further deterioration and is likely to cause death, but he is not 100% sure, sometimes the body can establish a balance, but the pressure is deleterious to the brain, causing pain and distress.

Before the blockage Dr. Hill found very little capability but to him Stephen seemed happy, responded to others and smiled or laughed when stimulated. He seemed to be in contact with his surroundings and capable of rudimentary communication, such as babbling. He seemed to show some response to verbal interaction. He believes that surgery would be in the child's best interest because "he is a happy little fellow despite his handicaps."

2) Dr. Patrick Murray is the neurosurgeon who was originally scheduled to perform the surgery until the consents were withdrawn. He will still do it if the parents consent or he is given lawful authority. He saw Stephen on 15 February 1983 in his padded cot. He seemed to be responding to pain but not to sound or light. He had a withdrawal response in his limbs. He found the shunt was not functioning and intercranial pressure was raised. He phoned the mother and she agreed to the surgery. Surgery was booked pending parental consent. On the planned day the parents asked him not to do it - to allow him to die with dignity. They said they had hoped for an opportunity like this

to allow him to die with dignity. He thought it was a "reasoned decision". On medical grounds he thinks the surgery should be done but on the second level, taking in the moral and the ethical considerations raised by the parents' attitude, he thinks that surgery would be "an extraordinary surgical intervention". He thinks there is no hope for improvement after surgery - that is, he will live but will remain in his pre-operative state.

Dr. Murray had two further conversations with the mother which are of significance. On the day of Stephen's apprehension both parents were very distressed. The mother told him that in the event he (the doctor) was forced to do the operation she would do something to Stephen herself. On the last day of the Provincial Court hearing the mother phoned Dr. Murray, sobbing, and expressed the feeling that the result would be contrary to her wishes. She asked the doctor if he did the operation would he not put Stephen to sleep.

Dr. Murray does abut 60 shunt operations a year. It is not a particularly difficult operation in the hands of an expert.

3) Dr. Doreen McConnell is a pediatric specialist working at Sunnyhill for 3-1/2 years. She knows all 60 children there as individuals. 11 of them are in about the same condition as Stephen. She first saw Stephen in 1980 and in February 1982 he

became an extended care patient under her care. She sees him as generally happy, when touched he smiles. "In his environment he is a happy child". She relies on her consultations with other staff members - teachers and physiotherapists - who confirm this view.

Before the blockage Stephen's general health was good, he was fully conscious and responded to a touch. There were no contractions of his joints, he sat in a regular wheelchair with an insert, he could hold his head up. He was capable of further development. She sees great changes in such children with schooling and therapy. She does not consider it terrible that he needs diapers - many adults do and the diapers are now easily disposable. She thinks he will be a candidate for toilet training in the future. The parents have never asked to see her although she does talk to parents when asked by them. There is no record of him being home overnight, although other parents can and do take their children home.

She tried to persuade the parents to allow surgery. The father said the boy was in constant pain. Dr. McConnell said "No, if you thought so you should have told me, I don't leave my patients in constant pain". The social worker present at the time said to the father that Stephen seemed happy and was making gains. The father said he had considered killing Stephen. The father said he had discussed this with Stephen himself and he had agreed. Dr. McConnell was upset and suggested he could be tried for murder and the father responded that he felt the law would be on his side.

Dr. McConnell believes the operation would be in Stephen's best interest and if performed there is no reason why Stephen would not have a normal life as a mentally retarded child.

Dr. McConnell does not think he will ever be able to speak, but that he will be able to communicate with wrist symbols or by a yes or no communicated with his head.

4) Kelly Comer is an occupational/physical therapist employed at Sunnyhill. She has been giving therapy sessions to Stephen since October 1982 - approximately 30 occasions once or twice a week from one-half to 1-1/2 hours per session. She submitted an affidavit and I allowed cross-examination upon it. I quote from her affidavit:

> 4. In or about the middle of December, 1982, I created a formal assessment and development program for Stephen. In my role as physiotherapist, I did the assessment, programing, and monitoring of a "gross motor program", the main component of which is head and trunk control needed for balancing, and of which another major component is exercises and positioning to maintain movement. In my role as occupational therapist, I performed the assessment, programing and monitoring of both a feeding program, and an equipment program, which equipment program included an insert within a wheelchair, tray and accessories on wheelchair, prone board and gaiter splints.
>
> 5. I have observed the following of Stephen:
>
> (a) Gross Motor Skills:
>
> (i) Independently rolls from stomach to back;
>
> (ii) independently rolls from back to either side;
>
> (iii) independently balances in sitting on a mat;
>
> (iv) Has balance reactions on his stomach and on his back;
>
> (v) Has protective responses to his side, in sitting, albeit on an inconsistent basis;

(vi) Has clapping and tapping ability, (bringing his two hands together or against a tray);

(vii) Will pull up from a supine to a sitting position, with assistance;

(b) Feeding Skills:

(i) Does not exhibit primitive reflexes;

(ii) Is dependent in the feeding process, although he participates voluntarily, if stimulated, in the non-reflexive manner, including:

(A) From a head-down position, Stephen will respond to a spoon touched to the side of his mouth by lifting his head up, and opening his mouth and clearing a spoon of food with his lips;

(B) Indicating, in my opinion, his being full with a meal, by not lifting his head or opening his mouth;

(C) Closing his lip on the edge of a cup to drink, as a refinement from biting the edge as he was initially doing;

(c) Equipment:

(i) From his wheelchair, with a foam and plywood insert to serve as a support, Stephen initially had a headrest, hip belt, shoulder and chest strap, but, except for the hip belt and with exceptions for meals, the foregoing has been removed. They were removed in late October, 1982, and I would infer that their removal demonstrates progress from an earlier point, before I met Stephen;

(ii) The tray was installed, on the wheelchair, in response to Stephen's ability to reach out and manipulate objects with his hands. Further a dowel apparatus has been fabricated to suspend objects from the top of the dowel, over the tray, in the expectation that Stephen will be able to manipulate objects suspended therefrom;

> (iii) A "prone board" has been provided for Stephen to stand on, towards aiding bone and joint formation;
>
> (iv) Stephen is gradually withdrawing from the use of gaiter splints, which were provided to prevent bending of the elbows and the often subsequent bringing of the hands to his mouth, which would have led to minor health problems as well as distracting Stephen from other tasks;
>
> (d) Vocalization Skills:
>
> (i) Stephen is able to make sounds. If the sounds are repeated back to him, he will almost always laugh and giggle and repeat the sounds;
>
> (ii) I have never, before the shunt problem which arose in February of 1983, seen or heard any wailing, crying, or moaning from Stephen, at any time, including during visits to the classroom and lunch room of Marg Miller.
>
> 6. From the observations I have made as set out in the previous paragraph, I believe that Stephen exhibits a degree of adaptive behaviour. Adaptive behaviour is a behavior observed in response to or influenced by stimulus, and I therefore believe Stephen must be aware of his environment where the stimulus originates. I believe, in many cases, Stephen's behaviour, be it motoric or verbal, is voluntary.
>
> 7. I have not had any contact with Stephen's parents, nor have received any indication of their interest in him, while at the Hospital.

Cross-examination of her did not diminish her affidavit.

5) A similar picture emerged from the evidence of Margaret Miller, Stephen's teacher at Sunnyhill who has seen him on a daily basis for 4-1/2 hours each day since September 1982. She has been working with multi-handicapped children for 10 years. I quote from her affidavit:

6. THAT in September of 1982 when Stephen was presented to my class at school, he appeared to be a grossly understimulated child who constantly sucked his hands.

7. THAT I was able to observe that within a period of a few weeks Stephen was able to show a very good response to the verbal command, "No Stephen, hands out". This situation progressed to the point that by January, 1983 on such command, Stephen would take his hands out of his mouth for periods of up to thirty (30) minutes.

8. THAT as a result of Stephen's progress with respect to verbal commands to take his hands from his mouth, he was chosen as the only child out of fifty (50) or more children at the Sunnyhill School, for daily one-to-one music therapy. I arranged this due to the belief that Stephen was one child who would benefit very quickly from this type of intervention: the rational for this was that Stephen's hand-sucking clearly indicated that he was seeking stimulation and his response to our request for hands out, showed that he was open to new ways to obtain stimulation.

9. THAT during the course of my involvement with STEPHEN DAWSON, I observed that he obtained great pleasure and smiled a great deal in vocalizing sounds, particularly the sounds "SSS", "K" and "HU". The fact that Stephen would attempt to copy these sounds when made by other individuals plainly showed that he was able to respond to his environment and make progress towards the rudiments of social interaction.

10. THAT prior to the discovery of STEPHEN DAWSON's blocked shunt, I did not notice Stephen to ever be in pain as he always appeared to be a fairly happy child and was never observed crying.

11. THAT during my involvement with STEPHEN DAWSON, not only did he progress to the stage of removing his hands from his mouth, he also began to interact with his environment in various ways including clapping on his chair tray and learning to work the levers on an electronic toy which would operate a fan or tape-recorder.

12. THAT I verily believe that STEPHEN DAWSON's fairly quick response to stimulous in his environment indicates that he was previously grossly understimulated and has more potential than he previously exhibited.

> 13. THAT during my involvement with STEPHEN DAWSON, he appeared to be emotionally well off in that he was able to both give and receive pleasure. In particular, he would smile and vocalize in response to social overtures; and he would also show great pleasure in being cuddled and being played with. In fact I noticed that he greatly enjoyed physical contact with others and being swung around as in a child's normal airplane-ride type play.
>
> 14. THAT STEPHEN DAWSON is not the most severely impaired child in my classroom, either physically or mentally. In particular he is physically the most able child in my class of eleven (11) students, he is not deaf, and prior to his shunt blockage he had light perception.

6) Dr. Sydney Segal is a pediatric specialist who is familiar with Stephen. He filed an affidavit but was not cross-examined. I quote:

> 8. THAT so long as this surgery is delayed Stephen Dawson's condition will continue to deteriorate and he may not die, surviving with severe distress.
>
> 9. THAT if the shunt is changed, the life of Stephen Dawson will be prolonged.

7) Dr. John Crichton is a pediatrician, called by the parents, who specializes in pediatric neurology. He examined Stephen on 11 March 1983 at the behest of the Superintendent to see if it was likely that he would run into difficulty over the weekend. He had never seen Stephen before. He saw signs of increased cranial pressure and concluded that he would improve to some extent if the pressure was released. He does not know if he will improve to his previous condition. In his situation he sees Stephen as being on a knife edge. There has been some "coning" that is caused by downward pressure on the brain stem.

More coning could kill him. Dr. Crichton cannot tell if Stephen will necessarily die without the operation.

8) Dr. Bizma Tischler was called by the Child Advocate appointed by the Attorney General. She is a pediatric specialist who for 15 years has been the Medical Director of Woodlands Hospital where are found mostly severely and profoundly retarded children and adults. She has never seen Stephen but has spoken to Drs. Hill and Murray. She has not seen his brain scan.

Without a shunt revision she believes that Stepehn will not necessarily die but may live for months or years. If he lives without a shunt there will be additional brain damage, his function level will decrease, he will suffer pain from headaches mainly. A state of equilibrium may be reached in that the fluid production may decrease. She has a 12 year old patient in Woodlands who is congenitally hydrocephalic who has a head circumference of 38" and requires complete bed care and nursing. He has never had a shunt.

In considering the application of the <u>parens patriae</u> jurisdiction I recognize that the central concern is to discover what is in Stephen's best interest. This is not a "right to die" situation where the courts are concerned with people who are terminally ill from incurable conditions. Rather it is a question of whether Stephen has the right to receive appropriate medical and surgical care of a relatively simple kind which will assure to him the continuation of his life, such as it is.

I am satisfied that the laws of our society are structured to preserve, protect and maintain human life and that in the exercise of its inherent jurisdiction this court could not sanction the termination of a life except for the most coercive reasons. The presumption must be in favour of life. Neither could this court sanction the wilful withholding of surgical therapy where such withholding could result not necessarily in death but in a prolongation of life for an indeterminate time but in a more impoverished and more agonizing form.

I do not think that it lies within the perogative of any parent or of this court to look down upon a disadvantaged person and judge the quality of that person's life to be so low as not to be deserving of continuance.

The matter was well put in an American decision - <u>In the Matter of Eugene Weberlist</u> 360 N.Y.S. 2d 783 where Justice Asch said at p. 787:

> There is a strident cry in America to terminate the lives of <u>other</u> people - deemed physically or mentally defective . . . . Assuredly, one test of civilization is its concern with the survival of the unfittest, a reversal of Darwin's formulation . . . . In this case, the court must decide what its ward would choose, if he were in a position to make a sound judgment.

This last sentence puts it right. It is not appropriate for an external decision maker to apply his standards of what constitutes a livable life and exercise the right to impose death if that standard is not met in his estimation. The decision can only be made in the context of the disabled person viewing the worthwhileness or otherwise of his life in its own context as a disabled person - and in that context he would not compare his life with that of a person enjoying normal advantages. He would know nothing of a normal person's life having never experienced it.

An English case which raised rather similar problems is In Re B, The Weekly Law Reports, November 27, 1981, in the Court of Appeal and I quote from the reasons of Templeman, L.J.:

> It concerns a little girl who was born on July 28, 1981. She was born suffering from Down's syndrome, which means that she will be a mongol. She was also born with an intestinal blockage which will be fatal unless it is operated upon. When the parents were informed of the condition of the child they took the view that it would be unkind to this child to operate upon her, and that the best thing to do was for her not to have the operation, in which case she would die within a few days. During those few days she could be kept from pain and suffering by sedation. They took the view that would be the kindest thing in the interests of the child. They so informed the doctors at the hospital, and refused to consent to the operation taking place. It is agreed on all hands that the parents came to this decision with great sorrow. It was a firm decision: they genuinely believed that it was in the best interests of this child. . . .
>
> What happened then was that the doctors being informed that the parents would not consent to the operation contacted the local authority who very properly made the child a ward of court and asked the judge to give care and control to the local authority and to authorise them to direct that the operation be carried out, and the judge did so direct. But when the child was moved from the hospital where it was born to another hospital for the purposes of the operation a difference of medical opinion developed. The surgeon who was to perform the operation declined to do so when he was informed the parents objected.

This morning the judge was asked to decide whether to continue his order that the operation should be performed or whether to revoke that order, and the position is now stark. The evidence, as I have said, is that if this little girl does not have this operation she will die within a matter of days. If she has the operation there is a possibility that she will suffer heart trouble as a result and that she may die within two or three months. But if she has the operation and it is successful, she has Down's syndrome, she is mongoloid, and the present evidence is that her life expectancy is short, about 20 to 30 years.

The parents say that no one can tell what will be the life of a mongoloid child who survives during that 20 or 30 years, but one thing is certain. She will be very handicapped mentally and physically and no one can expect that she will have anything like a normal existence. They make that point not because of the difficulties which will be occasioned to them but in the child's interest. This is not a case in which the court is concerned with whether arrangements could or could not be made for the care of this child, if she lives, during the next 20 or 30 years; the local authority is confident that the parents having for good reason decided that it is in the child's best interests that the operation should not be performed, nevertheless good adoption arrangements could be made and that in so far as any mongol child can be provided with a happy life then such a happy life can be provided.

The question which this court has to determine is whether it is in the interests of this child to be allowed to die within the next week or to have the operation in which case if she lives she will be a mongoloid child, but no one can say to what extent her mental or physical defects will be apparent. No one can say whether she will suffer or whether she will be happy in part. On the one hand the probability is that she will not be a cabbage as it is called when people's faculties are entirely destroyed. On the other hand it is certain that she will be very severely mentally and physically handicapped.

On behalf of the parents Mr. Gray has submitted very movingly, if I may say so, that this is a case where nature has made its own arrangements to terminate a life which would not be fruitful and nature should not be interfered with. He has also submitted that in this kind of decision the views of responsible and caring parents, as these are, should be respected, and that their decision that it is better for the child to be allowed to die should be respected. Fortunately or unfortunately, in this particular case the decision no longer lies with the parents or with the doctors, but lies with the court. It is a decision which of course must be made in the light of the evidence and views expressed by the parents and the doctors, but at the end of the day it devolves on this court in this particular instance to decide whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die. There may be cases, I know not, of severe proved damage where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion, but in the present case the choice which lies before the court is this: whether to allow an operation to take place which may result in the child living for 20 or 30 years as a mongoloid or whether (and I think this must be brutally the result) to terminate the life of a mongoloid child because she also has an intestinal complaint. Faced with that choice I have no doubt that it is the duty of this court to decide that the child must live. The judge was much affected by the reasons given by the parents and came to the conclusion that their wishes ought to be respected. In my judgment he erred in that the duty of the court is to decide whether it is in the interests of the child that an operation should take place. The evidence in this case only goes to show that if the operation takes place and is successful then the child may live the normal span of a mongoloid child with the handicaps and defects and life of a mongol child, and it is not for this court to say that life of that description ought to be extinguished.

Accordingly the appeal must be allowed and the local authority must be authorised themselves to authorise and direct the operation to be carried out on the little girl.

I cannot accept their view that Stephen would be better off dead. If it is to be decided that "it is in the best interests of Stephen Dawson that his existence cease", then it must be decided that, for him, non-existence is the better alternative. This would mean regarding the life of a handicapped child as not only less valuable than the life of a normal child, but so much less valuable that it is not worth preserving. I tremble at contemplating the consequences if the lives of disabled persons are dependent upon such judgments.

To refer back to the words of Templeman, L.J. I cannot in conscience find that this is a case of severe proved damage "where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion". I am not satisfied that "the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die". Rather I believe that "the life of this child is still so imponderable that it would be wrong for her to be condemned to die".

There is not a simple choice here of allowing the child to live or die according to whether the shunt is implanted or not. There looms the awful possibility that without the shunt the child will endure in a state of progressing disability and pain. It is too simplistic to say that the child should be allowed to die in peace.

In conclusion I order that interim custody be granted to the Superintendent pending a hearing pursuant to s.13 of the Family and Child Service Act and while in that interim custody the surgical procedure be carried out pursuant to the authority of this court. The matter is remitted to the Provincial Court for the s.13 hearing.

Vancouver, B.C.
March 18, 1983.

I [illegible] fill
E[illegible].

Body and Victorian Culture (Cambridge, Mass.: Harvard University Press, 1978) Bruce Haley notes the Victorian obsessions with the body. *Mens sana in corpore sano* was to be achieved by school sports, at least for the new upper-class, leisured Englishman, who, as a schoolboy, had the discipline of the classroom and the playing fields and, when later employed, had money enough to maintain that fitness by fox hunting or mountain climbing in the Swiss Alps. These sports were not only physical but moral — the building of character that would make a "muscular Christian." Today's efforts at fitness in a secularized mass culture of leisure, with its fine calculus of risks for getting sick, are perceived differently. The newly recommended behaviors (eating less, exercising more, not smoking) do seem self-denying in comparison with the incessantly advertised opportunities for gluttony, booze, cigarettes, and sloth that emanate from Madison Avenue. Like sports participants of the Victorian age, modern devotees of asceticism can feel a twinge of moral superiority, even perhaps of sacrifice, but with the added secret hope of a longer life. There is less of moral rectitude and more of pure survival.

It seems that we also want to accomplish body maintenance more expertly (if not more cheaply) while looking inside our fragile flesh — not so much to demystify it as to partake more deeply in its mystery. It is possible that the roots of this search may lie even deeper, in some innate survival instinct.

Given the modern belief that there is but one life to lead, this search for the healthy body may seem almost devotional. Think of those Sunday mornings when more joggers pass the churches than communicants enter. Even such titles as Mollen's *Run for Your Life* (New York: Doubleday, 1975) seem to be addressed to salvation, not to fear. Yet, in this secularized society, few would acknowledge these health behaviors to be religion in disguise. Could one naively argue that these behaviors may build character that, in keeping with today's culture, is biopsychological rather than religious? Jogging has its personal benefits in producing "highs" and increasing self-esteem. Does it help one get through yet another day in a society palpably less righteous than that of the 19th century, and at the same time hold to a vision of earthly salvation straight out of the Middle Ages?

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SPECIAL REPORT

THE AMERICAN ACADEMY OF PEDIATRICS COMMENTS ON THE "BABY DOE II" REGULATIONS

THE Department of Health and Human Services (DHHS) recently issued "Baby Doe II," a proposed rule designed to prevent hospitals from withholding food or medical care from handicapped infants. Born of a widely publicized incident in Bloomington, Indiana, involving a child with Down's syndrome and esophageal atresia, the rule is part of a larger controversy that has pitted right-to-life groups — presumably with the support of the Office of the President — against hospitals, pediatricians, and other physicians who question whether the federal government should have a role in the critical-care nursery. The DHHS' initial rule on the subject was struck down by Judge Gerhard Gesell of the U.S. District Court for the District of Columbia, because it lacked a rational, factual basis, and because the DHHS had failed to comply with procedural requirements on advance notice and comment.

Undeniably, the proposal raises serious legal and ethical issues. In the heat of moralistic and theoretical debate on these issues, however, it is sometimes easy to lose sight of the practical effects that the proposed rule would have on the medical care afforded critically ill infants and newborns. Much has been written on the legal and ethical aspects of the rule, but little attention has been focused on exactly how it would operate — how the DHHS intends to conduct hospital investigations and actually enforce its nondiscrimination standard. The Department's internal documents, and two little-publicized incidents occurring during litigation involving the first "Baby Doe" rule, create grave concerns about the government's latest proposal.

BACKGROUND: INVESTIGATIVE PROCEDURES

Last March, the DHHS published its first "Baby Doe" rule. As a condition of federal funding, the rule required hospitals to place poster-size notices in prominent positions in delivery rooms, nurseries, and maternity and pediatric wards, stating "DISCRIMINATORY FAILURE TO FEED OR CARE FOR HANDICAPPED INFANTS IN THIS FACILITY IS PROHIBITED BY FEDERAL LAW." The notices included a 24-hour, toll-free hotline number, which anyone could call to report suspected hospital failures to provide food or medical care to such infants. The notices also promised anonymity to all callers. At the DHHS end, calls were answered with the words, "Infant Doe Hotline."

Internal memoranda obtained in the course of litigation on the rule revealed no DHHS case or investigation in which a finding of discrimination was made. Rather, the record consisted primarily of law review and other theoretical articles, along with newspaper accounts of the "Baby Doe" incident. As Judge Gesell observed, notably absent from the record was any analysis or evaluation of the potentially disruptive effects of the rule on the medical care of critically ill infants.

Despite this sparse factual and analytical record, the DHHS approached the issue with a seemingly military zeal. To act on hotline calls, the Department created what it calls a "Special Assignment Baby Doe Squad." According to DHHS documents, squad members are to view "Baby Doe complaint cases" as the "highest priority," taking precedence over leave plans, normal working hours, personal plans, or other cases. Members are instructed to be available for travel on short notice, to master the procedures for obtaining travel tickets directly from airlines and obtaining motor-pool vehicles from the General Services Administration, and to possess a major credit card for emergency hotel charges. Numbered copies of "Baby Doe Complaint Investigation Standard Operating Procedures" are provided and are not to be duplicated or released outside the Department.

Upon receipt of a hotline complaint, the DHHS memoranda continued, one, two, or three squad members are to be prepared to be dispatched immediately to a hospital site, with one member assigned as "Team Leader." In the meantime, a "Baby Doe Coordinator" for the region in which the hospital is located is to initiate a "pre–on-site contact" by telephoning the hospital administrator to confirm the existence within the facility of the child who was the subject of the complaint. The coordinator is then to determine the infant's physical condition, diagnosis, prognosis, planned treatment, and the like — information that few, if any, hospitals would disclose by telephone under normal circumstances. If the Team Leader, on the basis of a "preliminary medical opinion" from a telephoned "medical expert," determines that the infant "is in imminent danger," he is charged with "immediately negotiat[ing] with the hospital" to provide medical treatment.

STRONG MEMORIAL AND VANDERBILT INCIDENTS

Affidavit testimony submitted during litigation describes the actual operation of these procedures during two DHHS investigations prompted by calls on the Infant Doe Hotline. The course of these investigations — one at Strong Memorial Hospital in Rochester, N.Y., and the other at Vanderbilt University Hospital in Nashville — suggests that the solution the DHHS intends to provide might be far more detrimental to the health and safety of infants than the problems giving rise to the investigation.

The Rochester incident, which formed the basis for an injunction against the rule covering New York State, was prompted by the admission to Strong Memorial Hospital of Siamese twins who had two heads and one trunk. An unidentified caller from another town, having read a newspaper account of the twins' admission and apparently suspecting that they might be denied food or medical care, called the DHHS hotline.

At approximately noon on March 29, 1983, the hospital was advised by telephone that a civil rights investigation was to be conducted. That afternoon, three investigators arrived at the hospital, two from New York and one from Washington. Despite advance requests by the hospital, the investigators brought with them no written requests for medical information and no statement of investigative authority, nor even any verification that a hotline call had been received.

The hospital complied with the investigators' requests for medical records, only to have the investigative team disagree among themselves about which office was entitled to the information. The investigators also arranged for a neonatologist to fly in from Norfolk, Va., at 10:00 p.m. that evening for consultation; he left the next morning, however, after discovering that the investigators had failed to obtain the parents' consent to examine the children. Although the neonatologist expressed full support for the medical decision making, level of parental involvement in that decision making, and overall management of the case, no commitment was given about when a final report would be issued.

In addition to the trauma caused by the birth of infants with profound congenital malformations, the parents were forced to deal with the investigation itself and with numerous local newspaper accounts of it. Parents of other critically ill children in the facility questioned the hospital administration on the adequacy of the care provided at Strong Memorial. On April 1, on the basis of newspaper reports and the belief that the facility was intentionally harming children, one family removed a seriously ill child from the hospital before his treatment had been completed.

The investigation at Vanderbilt University Hospital was broader in scope, having been initiated by a call to the hotline, charging that 10 named children at the hospital were not being fed or given proper medical treatment. An investigator from the DHHS office in Atlanta advised the hospital by telephone on the afternoon of March 23 that she wished to be provided, within one hour, with the current medical status, diagnosis, and prognosis of each of the children. The hospital stated that it would provide the information but could not do so in an hour. The investigator stated that an investigative team would be on the next plane to Nashville.

At 9:30 p.m., the team arrived at the hospital: two investigators from Atlanta, one from Washington, and a neonatologist from St. Louis. A meeting was convened with the team, the attending physicians for each of the 10 children, the chief of pediatrics, the chief pediatric resident, and the associate director for nursing; it ran from 9:30 to 11:45 p.m., and the medical care given each of the children was discussed. After the meeting, the physicians made rounds to visit each child. On the next day, from 8:00 a.m. until 4:00 p.m., the investigative team examined medical records and interviewed nursing staff, hospital administration staff, and the chief of pediatrics.

As at Rochester, the neonatologist reported that the medical care being given the children at Vanderbilt was exemplary in all respects. The investigators, however, promised no final report for 30 to 90 days.

The impact of the investigation on the hospital and the care provided was substantial. One patient remained in the pediatric intensive-care unit longer than necessary, because his chart was being reviewed by the investigators and hence was unavailable to the house staff to write discharge orders. The need to retrieve charts from the investigative team delayed the transporting of children from the pediatric intensive-care unit to the operating room. Laboratory reports had to be reordered. Six nurses were diverted from patient assignments for interviews with the investigative team; since several of these interviews occurred during shift changes, there were delays in providing patient reports to nurses on the next shift. The chief of pediatrics worked on the investigation for 8 hours; the associate nursing director for 18 hours; the chief pediatric resident for 10 hours; and six nurses for 3 hours. Their time would otherwise have been spent caring for patients.

THE CURRENT DHHS PROPOSAL

The new DHHS "Baby Doe" proposal differs from the previous one in two respects only: the nondiscrimination notices that hospitals would have to post are somewhat smaller (8½ by 11 inches rather than 14 by 17), and they would have to be placed in the nurses' station rather than elsewhere in the hospital wards. These changes, of course, do little to obviate the detrimental effects of the previous rule.

Countless questions of a legal and theoretical nature remain: for example, whether Congress intended that Section 504 of the Rehabilitation Act (a statute traditionally invoked to require the building of wheelchair ramps and the provision of sign-language interpreters) should be extended to authorize a government role in critical-care nurseries. Similarly, the proposal requests comment on a number of issues that might be labeled as "ethical" in nature — i.e., whether medical decision making can or should be influenced by economic, emotional, or marital concerns. Of major concern is the possible extension of the rule to other, equally complex situations involving life-sustaining treatment of adults. In the end, however, it may be the more practical considerations that determine the fate of the rule: Can the federal government effectively dictate and enforce a standard of medical decision making to apply to every desperately ill infant in every hospital, without in the process jeopardizing the health of the very subjects it seeks to protect?

The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research — a distinguished panel of physicians, attorneys, and ethicists — concluded after an in-depth study that federal involvement in the treatment of defective infants could only produce excessively detailed regulation, with the potential for harming other hospital patients. Instead of federal involvement, the Commission recommended that the DHHS require hospitals to create institutional review boards to deal with individual cases and treatment decisions. In the interests of safeguarding the continuity of medical care provided to infants and of avoiding disruption of hospital procedures by heavy-handed and intrusive investigative techniques, the review-board approach provides a superior alternative.

Asking the questions, of course, is only half the battle. The burden now rests with the public and with those concerned with the medical treatment of critically ill infants and newborns, to respond to the DHHS' proposal. As Judge Gesell concluded in his opinion on the first "Baby Doe" rule, only through preservation of the democratic process of public comment "can good intentions be tempered by wisdom and experience."

JAMES E. STRAIN, M.D.
President, American Academy of Pediatrics

Editor's note: Comments should be submitted in writing by September 6, 1983, to the Director, Office for Civil Rights, Department of Health and Human Services, 330 Independence Avenue S.W., Room 5400, Washington, DC 20201.

Fetal Research

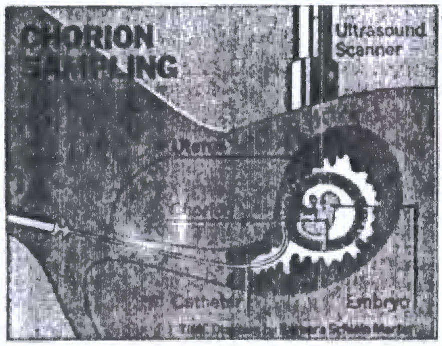
Gene Screen

Early fetal checkup

For Donna and Steven Roehl and Debbie and Maury Fisher, having a baby is a risky business. The Roehls both carry the gene for Niemann-Pick disease, a metabolic disorder that has already taken the life of their first child. The Fishers are carriers of Tay-Sachs disease, a fatal ailment that afflicts their two-year-old son. For both couples, the odds are one in four that any child they bear will be defective. When the two wives became pregnant earlier this year, they intended to undergo amniocentesis, a test to determine if the fetuses were normal. Each planned to abort if it was not.

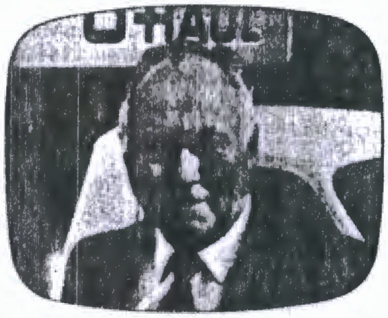
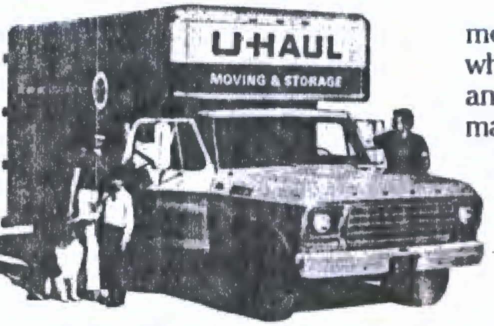
But amniocentesis usually cannot be done until the 16th or 17th week of pregnancy, when there is enough amniotic fluid to obtain a sample safely via a needle through the abdomen. Results are not available for another four weeks. Eager to avoid five months of anxious waiting, the two women volunteered for a new, early test of fetal health, under study at Michael Reese Hospital in Chicago. Fisher had the procedure in her ninth week "and found out the next day that my baby did not have Tay-Sachs." Roehl also got good news, fast.

The test, called chorionic villi sampling (CVS), is a painless procedure and can be done in a physician's office as early as the fifth week of pregnancy. To perform it, the obstetrician inserts a long thin tube through the vagina into the uterus. A second doctor, following the procedure on an ultrasound monitor, helps the obstetrician position the catheter between the lining of the uterus and the chorion, a layer of tissue that surrounds the embryo during the first two months and later develops into the placenta. The goal is to suction up a sample of the chorionic villi, finger-like projections of tissue that transfer oxygen, nutrients and waste between mother and embryo. "It's like vacuuming a shag rug; you get about half a dozen villi," explains Dr. Laird Jackson of Philadelphia's Jefferson Medical College, which has helped pioneer the technique in the U.S. Since the tiny chorion sample is composed of the same cells as the fetus, genetic defects present in the child should show up in laboratory analysis.



Dr. Eugene Pergament of Michael Reese is convinced that CVS "will eventually replace amniocentesis as the first line of genetic diagnosis." Earlier detection not only means less anxiety for the mother, it also means that should she choose to terminate the pregnancy, she can have a simple outpatient abortion after six to eight weeks rather than a far more complex one at five months, requiring hospitalization. "And no matter how you feel about abortion," says Jackson, "there is a difference in our perception of pregnancy at eight weeks and at 20."

The cost of CVS, which will soon be available at some 35 hospitals, is $550 to $800, about the same as amniocentesis. The risks, though not fully known, are probably also the same: one in 200 women who have undergone amniocentesis suffers complications (infection, for example) that may lead to miscarriage. For this reason the new test will be recommended only for women known to have a high risk of delivering an abnormal baby, including the growing number who wait until age 35 or later to have their first child. CVS may some day prove to be valuable for another reason, says Dorothy Davis, spokesperson for the March of Dimes. Early detection of genetic defects may make it possible for doctors to intervene and correct problems while the child is in the womb. ■

NO. WDS.—CL. OF SVC.	PD. OR COLL.	CASH NO.	CHARGE TO THE ACCOUNT OF	THIS MESSAGE WILL BE SENT AS A TELEGRAM UNLESS IT IS OTHERWISE INDICATED.	PRESS DPR	PRESS NPR	OVER NIGHT TELEGRAM

Send the following message, subject to the Telegraph Company's conditions, rules and regulations, which are on file with regulatory authorities.

MAILGRAM

October 28, 1983

The President
The White House
Washington, D.C.

On Monday, October 31st, it will be ten days since the U.S. DHHS requested medical records from University Hospital, Stoney Brook, New York, on "Baby Jane Doe", a spina bifida baby being denied surgery,and fourteen days since DHHS first knew of the denial. Neither records nor access to the baby have been obtained by DHHS.

This case is very similar to the Bloomington "Baby Doe" case which eighteen months ago caused you to issue an order to HHS and Justice to ensure that federal laws will be vigorously enforced except that your administration has accomplished no protection whatsoever for this baby.

We plead with you to become personally involved in this case and at a minimum:

1. Order DHHS to go to court to get the medical records and an independent medical evaluation including a physical examination by its pediatric neurosurgeon consultant. Dr. Fred Epstein of NYU Medical Center has been prepared to do the evaluation for seven days.
2. Order the Justice Department to begin an investigation as to whether this case is a violation of 18 USC 241, Conspiracy against rights of citizens.

This baby is still alive. Please act now.

(Mrs.) Judie Brown
President
American Life Lobby, Inc.
426 C St, NE
Washington, D.C. 20002

file

9-19-83

Thank you! HYDE OK! (IN HOUSE)

Alert

American Life Lobby, Inc., P.O. Box 490, Stafford, VA 22554 (703) 659-4171

ALERT............HYDE AMENDMENT........ALERT

Dear Friend of Life:

In the next 2 weeks, there is likely to be action taken on four bills of interest to Pro-Lifers; HR 3913, the FY 1984 Labor HHS Appropriations Bill; HR 3222, the FY 1984 Commerce Justice Appropriation Bill; HR 2350, the Reauthorization for the National Institute of Health and; HR Res. 367 the First Continuing Resolution for FY 1984.

HR 3913

The bill was passed by the U.S. House of Representatives. The bill contains the Hyde/Conte Amendment which bans funding for all abortions with no exceptions.

Action Required: Call both your U.S. Senators and urge them to vote to keep the Hyde/Conte Amendment in this bill and to INCLUDE IT IN THE CONTINUING RESOLUTION AS WELL.

HR 3222

This bill as reported from the House Committee contained $296 million for the Legal Services Corporation (see the August 1983 A.L.L. About Issues, pp. 12-13) On a point of order made by Congressman Sensenbrenner (WI-9) this entire amount of money was deleted from the bill because it was unauthorized by law.

Action Required: Write to your Congressman and to both of your Senators urging them to be sure that this money remains deleted from this bill and THAT THESE FUNDS ARE NOT INCLUDED IN THE FIRST CONTINUING RESOLUTION FOR FY 1984.

HR 2350

Congressman Dannemeyer will offer his amendment to ban the use of Federal Health Research funds from being used to experiment on unborn babies unless the experimentation will benefit that particular baby. It is unclear when the House of Representatives will act on this bill and amendment. Therefore...

September 15 - 2P.M. - by a vote of 231-184 you retained the new Hyde Amendment - no life of the mother!

American Life Lobby mailed 6,000 Alerts on this matter during the recess and you did it.

Praise God & get to work!

Judie Brown

P.S. Am in Rome for an international leadership conference hosted by ALERT's International division: PLAN. Pray for us.

Action Required: First, call your Congressmand and urge him to vote for the Dannemeyer Amendment to HR 2350 with no changes. Then, write to your Congressman to vote for the Dannemeyer Amendment, unchanged, to stop, before it starts, fetal experimentation that is going on in Europe already. Send him a copy of the enclosed articles from the Cork Examiner (Ireland).

HJ Res. 367

Action Required: ~~Write seperate letters to~~ Call your Congressman and to both of your Senators saying that when they act on the First Continuing Resolution you want them to vote to:

1. Keep the Hyde Amendment, unchanged, in the bill.
2. Add the Smith/Ashbrook Amendment to ban federal payments for health insurance that covers abortion.
3. To delete all funds for the Legal Services Corporation consistent with the action of the House of Representatives on September 19, 1983.

The Cork Examiner

No. 50,372 THURSDAY MORNING, AUGUST 25, 1983 Price 32p (inc. 5.98p VAT)

Foetuses' experiments

By Val Dorgan

Laboratories in Europe, which serve the cosmetic industries in the preparation of beauty products, are experimenting on live human foetuses.

This horrific claim is made in an as yet unpublished report to a Committee of the European Parliament, in the possession of the *Examiner*.

The report, which makes harrowing reading, has been compiled by an Italian Christian Democrat member of the Parliament, Alberto Ghergo, for the Parliament's Research Committee. He has called for an EEC directive banning all commercial activity involving human foetuses.

In his report — as yet to be adopted by the Research Committee — the Italian MEP says that in (unnamed) European embroyological laboratories experiments are being carried out on foetuses of between 12 and 21 weeks old. These are removed whole and alive by means of hysterectomy (Caesarean Section). He does not name the EEC countries involved.

The embroyos are dissected in order to remove certain organs (pancreas, thymus, brain, etc.), which are frozen by liquid nitrogen vapours. Other embroyos are frozen on extraction from the mothers womb to be set aside for various uses.

According to his report, the use of foetuses has given rise to a dense network of economic interests "ranging from traffic in them, with financial incentives to encourage mothers to become donors, to laboratory manipulation."

Mr. Ghergo said the laboratories experimenting in live embroyos served the cosmetic industries in the preparation of beauty products such as powders and creams. They also serve allegedly scientific products for rejuvenation and anti-diabetic purposes. Other laboratories claimed to be concerned only with research.

The Italian Parliamentarian's report must first be approved by the Research Committee before it is referred to the Assembly's Legal Committee. If endorsed there, it will be submitted for debate in the Parliament. But this could take as long as a year and a discussion on the issue may not come in the lifetime of the present body whose term of office expires next summer.

The Parliament could advise the European Commission to study the subject in conjunction with national experts in order to establish European standards that would guarantee, in accordance with general ethical principles, the inviolability "of the dignity and the physical and moral integrity of all human beings."

Mr. Ghergo's report was commissioned for the Research Committee, following the submission of two resolutions to the Assembly concerning increasing numbers of experiments on human embroyos taken live from the womb, and another motion warning of the dangers of cloning experiments or genetic manipulation of humans.

The resolutions were supported by Fine Gael's Mark Clinton and Tom O'Donnell, members of the Christian Democrat Group, who were responsible for one of the resolutions. See Val Dorgan Column Page 5.

(CORK, IRELAND)

Page 6 **Cork Examiner, Thursday, August 25, 1983**

Time to end this nightmare

AS far as Irish people are concerned, the most extraordinary element about the report that experiments are being carried out in Europe on live human embryos, is that it seems to have been treated in such low key fashion by members of the European Parliament and Europeans generally.

People here can only recoil in absolute horror at the information contained in the report of the Italian MEP, Alberto Ghergo. He has said that these experiments are being conducted in European laboratories servicing the cosmetic industry and supplying it with materials for beauty aids.

The European Parliament's interest in what was described as "the increasing number of experiments on human embroyos taken live from the womb" goes back to last January.

The European People's Party — of which the Social Democrats, Fine Gael's group in the Assembly, are members — tabled a resolution in the ten-nations assembly urging member-States to ban any use of living embroyos for scientific as well as commercial purposes.

Two Fine Gael MEPs, Deputy Tom O'Donnell and Mark Clinton, were among those who put their names to the resolution, subsequently given for investigation to the Research Committee of the Parliament, which appointed Mr. Ghergo for the task.

A few months later, a German Socialist, Fritz Gautier, put down a similar resolution expressing his concern at the genetic manipulation or cloning of animals and the potential expansion of this to human beings.

The resolution got little enough publicity at the time because, in fact, similar resolutions have been under discussion in various other international institutions, and in the individual member states. But there appears to be little or no knowledge of the subject here.

As long ago as 1978, the Council of Europe, of which Ireland is a member, adopted a resolution recommending the member States to lay down special rules for the protection of embryos. This was followed by a parliamentary public hearing on genetic manipulation organised by the Council of Europe two years ago in Copenhagen. Its aim was to provide European legislatures with the most complete and up-to-date information on those aspects of genetics involving human life.

Churches, various associations of scientists, doctors, lawyers and psychologists have spoken out in the last few years against practices leading to what Mr. Ghergo calls the "manipulation of live and dead human foetuses, where these practices violated the dignity of the human person."

But it would seem that Mr. Ghergo's report, which must first be submitted for the approval of the Assembly's Research Committee, then approved by the Legal Committee before reaching the floor of the house, may not even be discussed by the present parliament, the first directly elected by the people of the Community. It ends its term next summer.

The Research Committee have not yet adopted the report as their option and, in fact, it is not even tentatively listed for the next meeting of the Legal Committee which takes place in September.

The Irish members of the Research Committee are Sean Flanagan (FF) and Brendan Halligan (Labour), with Paddy Lalor (FF) and Seamus Pattison (Labour) as substitutes. It is possible they may insist on a greater sense of urgency in considering the malpractices highlighted by the Italian MEP. Perhaps more than anything else, what Mr. Ghergo's report serves to highlight is the great gap in attitudes between the Parliamentarians from this country and the majority of those in other member States towards the whole issue of abortion.

It is notable that in his resolution, the Italian representative feels obliged to "urge member States to ban any use of living embryos for scientific as well as commercial purposes, allowing surgical operations only for therapeutic purposes in the interests of mother and child."

The inference would seem to be that while the most hardened pro-abortionist might, as a public representative, stop at condoning experiments on human embryos for beauty aids, he (or she) might justify it on scientific grounds.

Perhaps this public indifference is mirrored in the relaxed reaction of the European Parliament to the subject. The seemingly laissex faire attitude of the EEC Assembly to the exploitation of the unborn, which has been in evidence for a number of years, may well be highlighted by anti-abortionists here. It would seem to indicate a diminishing regard for fundamental human dignity and human rights.

It will undoubtedly heighten suspicion, particularly amongst the anti-abortion lobby in this country, that the European Parliament is seeking to impose abortion legislation on us.

The Catholic hierarchy, in fact, have specifically warned that this is the case. Before direct elections for the European Parliament in 1979, they claimed there were elements within the Parliament who wished to see abortion in all EEC countries.

It was a charge denied by the then President of the Parliament, Madam Veil, the French Solialist, who was responsible for introducing abortion legislation in her own country. She pointed out that the European Parliament was not legally entitled even to discuss abortion or divorce. In fact the Parliament not alone did so but effectively accepted abortion as part of women's rights legislation.

Realistically, no one close to Strasburg believes the Parliament, which generally has only advisory powers, could influence the EEC Council of Ministers, of which Ireland is a member, to force legislation for abortion here.

But if, as a body, it has any regard for human rights, the Parliament must show itself much more responsive to Mr. Ghergo's report, which surely has the power to shock and activate Irish MEPs, if not sufficiently large numbers of their European counterparts, to make it an issue in the life of the present parliament.

Val Dorgan column

American Life Lobby, Inc.

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(703) 659-4171

STATUS OF LEGISLATION REPORT: September 26, 1983 9:AM

BILL NUMBER	DESCRIPTION/STATUS	RECOMMENDED ACTION AT THIS TIME
S.J. Res. 8	Paramount Human Life Amendment. On Senate calendar. Available at any time for debate	None - not enough votes in the Senate to pass any amendment.
S.J. Res. 9	Unity Human Life Amendment. On Senate calendar. Available for debate at any time.	None - not enough voted in Senate to pass any amendment.
S.J. Res. 10	(Same as H.J. Res. 1) E.R.A. Referred to Senate Judiciary Subcommittee on the Constitution. Hearings held on May 26.	Oppose S.J. Res. 10. As presently worded, it will support abortion. Read our pamphlet ERA-THE ABORTION CONNECTION.
S.26	Human Life Bill. On the Senate calendar. Available for debate at any time. This bill has been changed and is now the text of S.467, The Respect Life Act.	This is an excellent bill which requires more support.
S. 242	(H.R.3021) Health Insurance for Unemployed Persons. On June 22, Senate Labor and Human Resources Committee by a 7-10 roll call vote defeated Metzenbaum (R-OH) amendment to delete the ban on use of this new health program to pay for abortion except to save the life of the mother. Pro-life victory!	We must retain ban on abortion when the bill comes to the Senate floor for a vote.
S. 372	(House: H.R.100) Fair Insurance Practices Act pending in Senate Committee on Commerce. Several days of hearings have been held. This bill contains a mandatory maternity and abortion coverage provision. On June 10, Senate Commerce Committee met to mark up this bill. A motion to postpone action "Permanently" was defeated 6 yeas to 7 nays. Subsequently action was postponed until a Government Accounting Office (GAO) study, requested by Senator Kassebaum (R-KS), is complete	None this time. Alert will be mailed when necessary.

S. 467	(House: H.R.618) Respect Life Act of 1983. Referred to Government Affairs Committee. No hearing scheduled at this time.	Your senator must be urged to publicly support this bill and become a co-sponsor.
S. 733	(House: H.R.2350) Re-authorization of National Institute of Health plus other program. No ban on fetal experimentation is in this bill at this time. Reported from committee. Senate Report 98-110	Fetal experimentation ban must be added. No action imminent.
S. 800	To Establish an Ocean and Coastal Impact Fund. Senators Jepsen and Helms announced June 23 that they intend to offer the text of S. 467 as an amendment to this bill. This has virtually killed the bill.	A pro-life victory! Write a thank-you note to Senators Jepsen and Helms
S. 951	Amends Title XX of the Coastal Security Act block grant for Social Services to welfare clients to provide health insurance for unemployed persons. Does not contain ban on abortion funding that is in S.242 or the Energy and Commerce version of H.R.3021. Senate Finance Committee Chairman Robert Dole (R-KS) marked up this bill July 12. The Grassley amendment to ban abortion funding under this was defeated 9 yeas to 10 nays.	Your senator must demand a ban on the use of taxpayer dollars for abortion. Write all senators now to vote for the Grassley amendment when this bill is debated on the floor.
S.1003	(House:H.R.1904) Child Abuse Prevention and Treatment Adoption Act. Senate Labor and Human Resources Committee adopted the Dodd (D-CT) amendment modified by Senators Hatch and Denton. This struck Erlenborn language and added a new Title II that, among other things, would allow US-DHHS to issue regulations requiring hospitals which have an ethics committee to decide on treatment or non-treatment of handicapped babies. This bill was reported favorably without a written report, which is being prepared now.	Stronger language is necessary on infant homicide (infanticide) if none is added. ALL will not support this bill. Write your senators and urge them to defeat this bill.
S.1133	(H.R.2909) To Re-Authorize the Legal Services Corporation for Three Years. The corporation's grantees have led the court battle for abortion on demand.	

(more)

S. 1344	(H.R.2350) To Re-Authorize the President's Commission on Bio-Medical Ethics.	ALL has vigorously opposed this commission and will continue to do so!
S.1646	FY 1984 Treasury, Post Office appropriation bill, reported from Appropriation Committee without the Smith/Ashbrook amendment. Floor action not expected until September.	Write your pro-life senator(s). Ask "Have you written a 'hold' letter on S.1646? If not, why not?" Send us a copy of the response you receive.
H.J.Res.1	(Senate:S.J.R.10) Equal Rights Amendment. Referred to House Judiciary Committee. One day of hearing held by Subcommittee July 13. No more expected until September.	ALL opposes this amendment to the Constitution. Read our pamphlet ERA-THE ABORTION CONNECTION.
H.R. 100	(Senate: S.373) Fair Insurance Practices Act. Transportation Committee in the House expected to act on this bill soon. Congressman Corcoran (R-IL) will, in full committee, offer an amendment to make the mandatory abortion coverage optional. Congressman Bliley (R-VA) will offer an amendment to require a separate additional premium to be paid for abortion coverage.	Action is imminent on this! Be sure your congressman is pressured to support all pro-life amendments.
H.R. 618	(S.467) Respect Life Act of 1983: Referred to for committees in the House in order to kill the bill. Discharge Petition No. 8 has been filed by Congressman Hyde and 218 signatures are needed on this petition so that we can bring the bill to the floor of the House for a vote, thus circumventing committees. Latest number of signers:80.	Urge your congressman to sign Discharge Petition No. 3 now. It is imperative that we get this bill to the floor for a vote and get the government out of the abortion business.
H.R. 1510	Immigration Reform Bill. Provides Medicaid (welfare) health benefits to formerly illegal aliens under some circumstances. Congressman Dannemeyer (R-CA), June 23, offered an amendment in committee to prohibit payment for abortions. Congressman Waxman (D-CA) offered an amendment to the Dannemeyer amendment to add rape and incest as exceptions. This addition was approved 26-13. This bill was then favorably reported with the prohibition on abortion except to save the life of the mother, rape and incest.	Urge your congressman to support the original Dennemeyer amendment only and to support every effort to remove rape and incest exceptions from the abortion amendment. Also, life of the mother must be clarified. Unity HLA language will accomplish all of this.

(more)

H.R. 1904	(Senate S.1003) Child Abuse and Prevention and Treatment Adoption Assistance Act. Includes a weak version of the Erlenborn anti-infanticide legislation of the 97th Congress. On May 5, the full House Education and Labor Committee further weakened the anti-infanticide provision by adopting the Miller (D-CA) amendment. This bill was favorably reported (House Report 98-159). NOTE: Any anti-infant homicide provision is no good unless it established a private right of third parties to intervene in a federal court to protect handicapped children.	Much stronger anti-infant-homicide language must be added, or ALL will not support this bill.
H.R. 2350	(Senate S.733 and S.1344) Re-Authorization of the National Institutes of Health (NIH) carries inadequate ban on fetal experimentation. Authored by Waxman (D-CA) as a substitute for the Dannemeyer (R-CA) amendment which banned fetal experimentation. Reported favorably by subcommittee. House Energy and Commerce full committee defeated the Dannemeyer amendment 28-18 on May 3. Bill favorably reported (House Report 98-191). This bill also contains re-authorization of the President's Commission on Bio-Medical Ethics similar to S.1334. Floor action on this bill is scheduled for week of August 1 or after September 12.	American Life Lobby strongly opposes this bill and will until a strong ban on fetal experimentation is added as a substitute for the weak Waxman version and until the President's Commission is removed from the bill. Act now! Call your Congressman to vote for the Dannemeyer amendment.
H.R. 2909	To re-authorize the Legal Services Corporation for three additional years. The Legal Services Corporation has led the court battle for abortion on demand.	Write your congressman to vote against this bill.
H.R. 3191	(S.1646) FY 1984 Treasury Post Office Appropriations Bill. The Ashbrook amendment to ban coverage for abortions was defeated on a voice vote in full House Appropriations Committee on June 2. On June 7, House Ruled Committee by a 7-5 vote authorized the Ashbrook amendment, offered by Rep. Chris Smith (R-NJ) was added to the bill by a vote of 226-182. However, the bill itself was defeated. The Treasury Appropriations subcommittee of the House will act on a new FY 1984 Treasury Appropriations Bill July 26, with full committee action tentatively set for July 28.	Your congressman must continue to support the Ashbrook amendment when it is offered again. Act now! Contact your congressman to vote to add the Ashbrook amendment to the new Treasury Appropriations Bill.

(more)

H.R. 3222	(S.1721) Commerce Justice, State and Judiciary Appropriation Bill. Included $296 million for the Legal Services Corporation that has led the fight to expand abortion rights (see August ALL ABOUT ISSUES pp 12-13). On Sept. 19, 1983 Congressman Sensenbrenner (WI-) raised a point of order that their was no authorization in law for this appropriation. The chair sustained the point of order and all $296 million was deleted from the bill.	Call both your senators to delete all funding for the Legal Services Corporation in S.1721. Call your congressman and both senators to delete all funding for Legal Services Corporation from the FY84 1st Continuing Resolution consistent with the House action of Sept. 19.
H.R. 3415	FY 1984 District of Columbia Appropriations Bill. Passed the House of Representative June 29. Traditionally this bill has banned the use of federal funds paid to District of Columbia government from being used to perform abortions except to save the life of the mother. The bill as reported from committee includes exceptions for rape and incest as well. Senate floor action is not expected on this bill until September.	Write both your senators to vote to take the rape and incest provisions out of the bill.
H.R. 3913	(S.). FY84 Labor, HHS Appropriation Bill. Reported from committee with the Hyde Amendment included with no changes. On Sept. 22 the Hyde Amendment was deleted on a point of order raised by Congressman AuCoin (D-OR1). Congressman AuCoin, Congressman Conte (R-MA-1) then offered an amendment that was identical to the Hyde Amendment but with no exception. Which passed 231-184.	Telephone both your senators' local offices and urge them to vote to keep Hyde/Conte amendment in H.R.3913 and the 1st Continuing Resolution, H.J.Res.
H.R.______	(S.1646) FY 1984 Treasury Appropriation Bill - Second Version (see H.R. 3191). On July 26, subcommittee marked up this bill including the Smith/Ashbrook Amendment to prohibit federal payment of health insurance premiums for federal employees if it covers abortion. Action expected week of September 12.	Write your congressman to vote to keep the Smith/Ashbrook amendment in this bill.

END

Contact American Life Government Liason office for additional information. Gary L. Curran - Legislative Consultant. (202) 546-5550 or write: American Life Lobby; 426 C Street NE; Washington, DC 20002

American Life Lobby, Inc.

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(703) 659-4171

October 20, 1983

Mr. John F. Cogan
Associate Director
Office of Management and Budget
246 Old Executive Office Bldg
Washington, D.C. 20503

Dear Mr. Cogan:

Thank you for taking the time yesterday to meet with me and my associate concerning Title X of the Public Health Service Act which expires on September 30, 1984.

In the past, over one billion dollars has been spent on this program. Nevertheless, illegitimacy and V.D. rates have continually climbed as have teenage pregnancy rates. Within the past two years, there have been two highly critical GAO reports on the waste and abuse and other questionable activities carried out with funds appropriated under this program. The Department of Health and Human Services has not changed a single comma of the guidelines nor proposed a single change in regulations to address the criticisms in either GAO report.

We, therefore, request that the Reagan Administration propose no new authorization for this program in its FY 1985 budget request when it is submitted to Congress in January of 1984.

This is a discretionary spending program that clearly has not achieved any of the purposes for which it was established, has had substantial waste and abuse documented, and is clearly an area where the Reagan Administration can reduce the budget deficit for FY 1985.

We recognize that however justified a "zeroing out" of this program may be, in the political world, elimination of it may not be in the realm of reality.

Therefore, we reluctantly, but very firmly, request that the Reagan Administration in its FY 1985 budget at least clean up the mess in the Title X program by doing at a minimum the following four things:

1. Any proposed reauthorization should be for one year; FY 1985 only.

A.L.L. . . . for God, for Life, for the Family, for the Nation

"But because thou art lukewarm, and neither cold, nor hot, I will begin to vomit thee out of my mouth" (Rev. 3:16)

2. The amount authorized should not exceed $98 million, the amount proposed by President Reagan for Title X in his budget amendments submitted to Congress on September 30, 1981. This is a cut from the amount appropriated under PL 98-107 of $42 million and is completely justified by costs associated with the waste and abuse documented in GAO reports, HRD 81-68 and HRD 82-106.

3. Section 1008 of the current Title X law should be rewritten to prohibit any funds from being used to perform abortions, abortion related services or lobbying particularly in favor of pro-abortion legislation (suggested text of a new section 1008 is attached). This will eliminate the 74 (attachment 2) abortion clinics (killing chambers) that are now being operated on the same sites with Title X clinics. It will also eliminate the lobbying that is orchestrated at Title X clinics. Note that GAO found evidence of lobbying at every one of the clinics they visited to check on this illegal activity.

4. In order to preserve parent's rights with respect to their minor children and in order that they may know the extent to which they are exposing themselves to financial ruin due to medical bills from the death and detrimental effects associated with prescription birth control drugs and devices, any Title X reauthorization bill proposed by the pro-family Reagan Administration should include the following new section:

   > "Section . None of the funds authorized by this title shall be used to supply directly, indirectly or by providing a prescription, birth control devices requiring a prescription to minor children under 18 years of age without prior parental consent."

   Note that a similar provision was enacted into law in Utah in 1980. In 1981, the teenage pregnancy rate was reduced by seven to eight percent compared with an increase of four and a half percent in the previous year.

As I mentioned at our meeting, I am also enclosing a legal opinion from our counsel showing why, over ten years, the prohibition contained in section 1008 has been whittled, in some cases with the complicity of DHHS bureaucrats, down to nothing and must, therefore, be rewritten to protect the taxpayers.

Further, I am enclosing a letter from Inspector General Kusserow as well as a listing of 74 federally funded clinics involved directly with abortion.

I have written to Mrs. Marjory Mecklenburg about the aforementioned list, and a copy of her response is attached.

In furtherance of the management initiatives to be taken by the Reagan Administration in connection with the formulation of the FY 1985 budget, I hope that you will "clean up the act" of Title X by taking the four minimal steps I have suggested.

Please call on me for further information.

With God for Life,

Judie Brown

(Mrs.) Judie Brown
President mb

enclosure
JB/mb

Attachment 2

SECTION 1008.....

(a) None of the funds authorized to be appropriated under this title shall be used to perform abortions or to provide abortion related services.

(b) None of the funds authorized in this title may be used to:

1) lobby or otherwise influence legislation pending in Congress or before any state or local legislative body

2) assist in supporting or defeating any referendum or initiative or other state or local ballot measure.

(c) The term "to lobby" in subsection (b) is defined as:

-insert definition contained in proposed A-122 regulations-

American Life Lobby, Inc.

NATIONAL HEADQUARTERS: MAILING ADDRESS: P.O. BOX 490, STAFFORD, VA 22554
OFFICES: ROUTE #6, BOX 162-F, STAFFORD, VA 22554
(703) 659-4171

September 15, 1983

The Honorable Margaret Heckler
Secretary of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, D.C. 20201

Dear Secretary Heckler,

As the administration formulates the FY 1985 Budget, you will be required to make recommendations concerning a very controversial program, the Title X Public Health Service Act, which expires on September 30, 1984.

Prior to making a decision about this program, I request a meeting with you to discuss the major deficiencies in this Title X program as evidenced by two highly critical government accounting office reports that show massive waste and abuse in this program.

The Administration must positively address the problems in this program prior to a final decision on the FY 1985 Budget.

A decision, by default or otherwise, to reauthorize this program will make a mockery of the 1980 promises to clean up the mess in Washington. Non-action against the waste and abuse in the Title X program will be a clear signal that the social pork barrel is alive and well, even in the Reagan Administration.

I look forward to meeting to discuss this vital subject.

With God for Life,

/s/

(Mrs.) Judie Brown
President

American Life Lobby, Inc.

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September 15, 1983

Mr. John A. Svahn
Assistant to the President for Policy Development
The White House
Washington, D.C. 20500

Dear Mr. Svahn,

As the administration formulates the FY 1985 Budget, you will be required to make recommendations concerning a very controversial program, the Title X Public Health Service Act, which expires on September 30, 1984.

Prior to making a decision about this program, I request a meeting with you to discuss the major deficiencies in this Title X program as evidenced by two highly critical government accounting office reports that show massive waste and abuse in this program.

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(Mrs.) Judie Brown
President

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September 15, 1983

Mr. John F. Cogan
Associate Director
Office of Management and Budget
262 Old Executive Office Building
Washington, D.C. 20500

Dear Mr. Cogan:

As the administration formulates the Fy 1985 Budget, you will be required to make recommendations concerning a very controversial program, the Title X Public Health Service Act, which expires on September 30, 1984.

Prior to making a decision about this program, I request a meeting with you to discuss the major deficiencies in this Title X program as evidenced by the two highly critical government accounting office reports that show massive waste and abuse in this program.

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With God for Life,

/s/

(Mrs.) Judie Brown
President

A.L.L. . . . for God, for Life, for the Family, for the Nation

"But because thou art lukewarm, and neither cold, nor hot, I will begin to vomit thee out of my mouth" (Rev. 3:16)

American Life Lobby, Inc.

NATIONAL HEADQUARTERS MAILING ADDRESS [illegible] ROUTE [illegible] 4171 STAFFORD, VA STAFFORD, VA 22[illegible]54

August 26, 1983

Michael Horowitz, Esq.
Chief Counsel
Office of Management and Budget
472 Old Executive Office Building
Washington, DC 20503

Dear Mr. Horowitz:

Thank you for setting up the meeting of August 25 and for spending time with us in the descriptions of your own problems as well as ours with the Circular A-122 revisions.

We would, having heard your comments, urge you to move forward. We will design our tactics around the actual text, when released, and use the comment period for our further input with your office.

We appreciate the fact that you understand our frustrations and feel that we now have a far better understanding of yours as well.

Again, thank you.

With God for Life,

(Mrs.) Judie Brown
President

cc: Morton Blackwell
Special Assistant to President Reagan

ALL ... for God, for Life, for the Family, for the Nation

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