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Controlling Genetic Disease Through Law

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Increasingly, state public health efforts are directed toward controlling genetic disease. While state infectious disease programs have a long history of legitimacy, state efforts to control genetic disease face unique practical and constitutional problems. This article explores the alternatives for the control of genetic disease, using infectious disease programs as a model for comparison. However, given the constitutional and privacy interests implicated by state actions in this area, the article concludes that private medical malpractice suits and voluntary measures may offer the most effective means for controlling genetic disease.

INTRODUCTION

Since the eradication of major infectious diseases in the United States,[1] public health officials have turned their atten-

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[1] Of the ten leading causes of death in this country, only one is of infectious

tion to controlling genetic diseases.[2] Checking heritable disease, however, has presented unique problems to the state; indeed, it is questionable whether these diseases are amenable to a prevention program. State statutes have been used effectively to help control infectious disease, and laws isolating the diseased from the healthy have a long history of legitimacy in the United States.[3] However, when the state is faced with a more insidious type of ailment, such as genetic disease, often the government's actions are less sure, its legal mandate less clearly defined. Consequently, the legitimacy of government attempts to cope with

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origin:

Ten Leading Causes of Death for 1979 Compared with 1978 and 1974-1978 in the U.S. Population

Causes of Death	Death Rate per 100,000 in 1979	1979 Death Rate as Percent of that in 1978	1979 Death Rate as Percent of that in 1974-1978
Major cardiovascular diseases	431.6	98	95
Diseases of heart	330.4	99	98
Ischemic and related heart diseases	251.9	[a]	[a]
Cerebrovascular diseases	76.5	97	87
Malignant neoplasms	183.5	101	104
Accidents and adverse effects	47.0	95	97
Motor vehicle accidents	23.6	96	104
Chronic obstructive pulmonary diseases and allied conditions	22.7	[a]	[a]
Pneumonia and influenza	20.0	75	76
Diabetes mellitus	15.0	100	93
Chronic liver disease and cirrhosis	13.5	99	92
Suicide	11.7	93	93
Homicide and legal intervention[b]	10.0	103	104
All Causes	866.2	98	97

[a] Because of changes due to the 9th Revision of cause of death coding procedures, the rank order comparability between death rates for these causes in 1979 and earlier years has been significantly affected.

[b] "Legal intervention" refers to deaths inflicted by law enforcement agents (including military on duty) and legal execution, but excluding deaths from injuries caused by civil insurrections.

METROPOLITAN LIFE INSURANCE COMPANY STATISTICAL BULLETIN, CURRENT MORTALITY REPORT 61 (Apr. - Jun., 1980).

[2] Most state infectious disease laws were originally enacted in the first quarter of this century. Genetic disease laws are of much later vintage. *See* notes 88-133 and accompanying text *infra*.

[3] *See* note 6 *infra*.

and to curtail genetic diseases are often challenged.

This article explores the unique nature of genetic disease, and how local governments have tried to prevent inherited health defects. It focuses on how this type of illness threatens a well-ordered society, and how its control endangers individual liberty. The article discusses several methods that states could use to control genetic disease. It also examines the efficacy of control through medical malpractice suits against physicians. These suggestions are contrasted against the current infectious disease programs in several states. The constant underlying value in all of these policies is human health. Yet other values — specifically, human dignity and individual freedom — must also be honored in social programs established to prevent genetic disease. This paper attempts to balance these needs, and suggests that under our system of constitutional law, the first line of defense against heritable disease lies with those responsible for creating new life — that is, ourselves.

I. The Infectious Disease Model

The state's duty to protect the health, safety, and welfare of its citizens is well-established.[4] This duty imparts a power — the police power — to the state, which it uses to ensure the necessary protection. The police power to protect is not unbridled;[5] its limits have been drawn by the United States Constitution, by statute, and by judicial decisions.

With few exceptions, courts have upheld the states' duty and

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[4] The acts of Congress, passed in 1796 and 1799 (U.S. Stat. 474, 619) empowering and directing the officers of the general government to conform to, and assist in the execution of the quarantine and health laws of a state, proceed, it is said, upon the idea that these laws are constitutional. It is undoubtedly true, that they do proceed upon that idea; and the constitutionality of such laws has never, so far we are informed, been denied. . . . [T]hey are treated as quarantines and health laws, are so denominated in the acts of Congress, and are considered as flowing from the acknowledged power of a state to provide for the health of its citizens.

Gibbons v. Ogden, 22 U.S. (9 Wheat.) 1, 205 (1824).

[5] Such laws do "not imply an acknowledgement that a state may rightfully regulate commerce with foreign nations, or among the states; for they do not imply that such laws are an exercise of that power, or enacted with a view to it." *Id.*

requisite power to prevent the spread of infectious disease.[6] States have imposed many requirements on citizens to protect public health. Reporting statutes, vaccination programs, and quarantine requirements, as well as measures for detention, removal, compulsory examination and sterilization of suspected carriers have all been imposed, and are discussed below. As is true of any exercise of police power, the legitimacy of the means the state chooses to control disease is crucial to the legitimacy of the control objective. The state has an array of measures available, ranging from mildly to highly restrictive. For example, it may fund a voluntary education program on infectious disease. At the other end of the spectrum, the state may impose mandatory measures such as quarantine to control a certain disease. Courts, therefore, look very carefully at the type of restriction imposed to see whether it is warranted.

A. The Constitutional Rationale

Most measures to control infectious disease are initiated by a local health authority under power derived from the state. When challenged, the measures have been upheld when the instituting authority has acted in a rational manner to meet a threat to the health of the populace.[7] When there has not been a reasonable basis for instituting public health controls that restrict individual freedom, courts have struck down the measures because they conflict with the Constitution.[8]

In balancing individual freedom against the state's need to protect the public health, courts have developed several criteria to determine whether health statutes are legitimate. In uphold-

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[6] It (state's police power) is generally said to extend to making regulations promotive of domestic order, morals, health and safety. It may also be admitted that the police powers of a state justifies the adoption of precautionary measures against social evils. Under it a state may legislate to prevent the spread of crime or pauperism, or disturbance of the peace. It may exclude from its limits convicts, paupers, idiots, lunatics, and persons likely to become a public charge, as well as persons afflicted by contagious or infectious diseases.

Railroad Co. v. Husen, 95 U.S. 465, 470-71 (1877). *See also* Barsky v. Board of Regents, 347 U.S. 442, 449 (1954); Jacobson v. Massachusetts, 197 U.S. 11, 25 (1905); Hawker v. New York, 170 U.S. 189, 191-95 (1898).

[7] *See, e.g.*, note 26 and accompanying text *infra*.

[8] *See, e.g.*, note 43 and accompanying text *infra*.

ing state power to protect public health at the expense of individual rights, courts have almost universally applied a minimum scrutiny test[9] for determining the constitutionality of various state actions. When courts apply this test, they presume the statute's validity and will not strike it down unless it lacks a reasonable relationship to a legitimate state interest or it is capricious, arbitrary, or otherwise unreasonable and oppressive.[10] Courts use these considerations when reviewing public health statutes: 1. Does the state have a duty to protect the public health? 2. Is that duty a legitimate legislative subject? 3. Does the health statute under consideration bear a rational and direct relationship to the objective? 4. Is the statute arbitrary or capricious? 5. If legislative classification results, is that classification rationally related to a legitimate state interest?[11] 6. Does the sweep of the statute go beyond what is required to achieve the objective? 7. Is either a suspect classification or a fundamental right involved?[12] As measures to control disease become more restrictive and invasive, the minimum scrutiny test becomes in-

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[9] *See, e.g.*, City of New Orleans v. Dukes, 427 U.S. 297, 303 (1976); Massachusetts Bd. of Retirement v. Murgia, 427 U.S. 307, 314-16 (1976). *See also* L. TRIBE, AMERICAN CONSTITUTIONAL LAW §§ 6-12, 16-2, 16-6 (1978).

[10] The rules by which this contention must be tested, as is shown by repeated decisions of this court, are these: 1. The equal protection clause of the Fourteenth Amendment does not take from the state the power to classify in the adoption of police laws, but admits of the exercise of a wide scope of discretion in that regard, and avoids what is done only when it is without any reasonable basis and therefore purely arbitrary. 2. A classification having some reasonable basis does not offend against that clause merely because it is not made with mathematical nicety or because in practice, it results in some inequality. 3. When the classification in such a law is called in question, if any state of facts reasonably can be conceived that would sustain it, the existence of that state of facts at the time the law was enacted must be assumed. 4. One who assails the classification in such a law must carry the burden of showing that it does not rest upon any reasonable basis, but is essentially arbitrary. (citations deleted)

Lindsley v. Natural Carbonic Gas Co., 220 U.S. 61, 78-79 (1911) (New York statute prohibiting extraction of mineral waters by certain means and for specific purposes upheld against equal protection challenge).

[11] This requirement is easily met, since a "statutory discrimination will not be set aside if any state of facts reasonably may be conceived to justify it." McGowan v. Maryland, 366 U.S. 420, 426 (1961) (exemptions from general prohibition of Sunday retail activities upheld against equal protection challenge).

[12] *See* note 71 and accompanying text *infra*.

creasingly difficult to apply.

B. Reportable Infectious Disease

At the lowest level of restriction in the infectious disease model are requirements that certain diseases be reported to a state public health authority. The list of reportable diseases may be statutorily explicit,[13] or it may be left to the discretion of the regulatory authority or even delegated to a local authority.[14]

Reporting imposes varying degrees of responsibility on citizens. Obviously, the burden falls most heavily upon physicians.[15] However, some statutes also require the head of a family to report an infectious disease.[16] Yet, no reporting statute requires action to aid or cure an individual stricken with a reportable infectious disease. Rather, the apparent objectives of the reporting statutes are to protect the health of the uninfected citizenry through the isolation of the infected group, and to supply epide-

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[13] Statutory mandates may be quite lengthy; for example, the Alabama code lists the following as reportable diseases:

> Actinomycosis, Anthrax, Chancoid, Chicken Pox, Cholera Asiatic, also Cholera Nostras when Asiatic Cholera is present or its importation threatened, Dengue, Diptheria, Dysentery (Amoebic), Dysentery (Baccilary), Epidemic Influenza, Favis, German Measles, Glanders, Gonorrhea, Granuloma Venereum, Leprosy, Lethargic Encephalitis, Lymphogranuloma Inguinale, Malaria, Measles, Meningitis (Tuberculose), Mumps, Ophthalmia Neonatorum (Conjunctivitis of newborn infants), Paragonimiasis (Endemic Hemoptysis), Paratyphoid Fever, Plague, Pneumonia (acute), Periomylitis (acute infectious), Rabies, Rocky Mountain Spotted or Tice Fever, Scarlet Fever, Septic Sore Throat, Smallpox, Syphilis, Tetanum, Trachoma, Trichinosis, Tuberculosis (all forms, the organ or part affected to be specified), Tularemia, Typhoid Fever, Typhus Fever, Undulent Fever, Whooping Cough, and Yellow Fever.

ALA. CODE §§ 22-11-1 (1975).

[14] Some states, however, merely delegate to the state public health authority the responsibility for determining which diseases must be reported. For example, the California code requires: "The State Department may establish a list of reportable diseases and this list may be changed at any time by the State Department." CAL. HEALTH & SAFETY CODE § 3123 (West 1979).

[15] *See, e.g.*, TEX. REV. CIV. STAT. ANN. art. 4477, Rule 1 (Vernon 1976) ("Every physician in this state shall report in writing or by an acknowledged telephone communication to the local health authority, immediately after his or her professional visit, each patient he or she shall have or suspect of suffering with any contagious disease.").

[16] *See, e.g.*, CAL. HEALTH & SAFETY CODE § 3123 (West 1979); TEX. REV. CIV. STAT. ANN. art. 4477, Rule 23 (Vernon 1976).

miological data so that states may differentiate epidemics from incidences of endemic disease. This identification is then used to justify escalation to more restrictive control measures.

Required reporting of infectious disease (other than venereal diseases) has not been challenged frequently in the courts.[17] Even though these laws lack confidentiality provisions,[18] they largely have been accepted as falling within the states' police power.

The model for infectious disease reporting statutes could also be used for genetic disease. But application of this model to genetic disease presents distinct problems. For example, if a group of genetic diseases is targeted as reportable, a discriminatory pattern may be created. Unlike infectious disease, which knows no ethnic, racial, or gender-based boundaries,[19] genetic disease is the result of heredity.[20] Second, reporting statutes for genetic disease often are formulated on the basis of availability of easy treatment,[21] not on incidence, prevalence, or severity of disease.[22] Consequently, if reporting laws for genetic disease are

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[17] However, more restrictive measures have been challenged. *See, e.g., Ex parte* Johnson, 40 Cal. App. 242, 180 P. 644 (2d Dist. 1919); District Board of T.E. etc., Trustees v. City of Lexington, 227 Ky. 7, 12 S.W.2d 348 (1928) (isolation and removal); Crayton v. Larabee, 220 N.Y. 493, 116 N.E. 355 (1917) (quarantine).

[18] *See, e.g.*, MINN. STAT. ANN. § 15.162 (West 1977 & Supp. 1981); N.H. REV. STAT. ANN. §§ 7A:1 to :5 (Supp. 1981); UTAH CODE ANN. § 63-2-59 (Supp. 1981); WASH. REV. CODE ANN. § 43.105.070 (1970).

[19] Infectious disease occasionally respects economic boundaries. Since its spread is often related to sanitation, poorer neighborhoods are often areas of contagion. Because neighborhoods often house single racial or ethnic groups, it appears that infectious disease affects only those groups. However, this is an economic and social vagary. A very few infectious diseases, such as coccidioidmycosis, are more *virulent* in certain racial groups. Genetics also plays a role in the spread of infectious diseases. For example, Africans who carry the sickle-cell trait seem to be protected from malaria.

[20] The laws on sickle cell anemia, a disease which affects blacks, illustrate this problem. *See* notes 105-115 and accompanying text *infra*.

[21] For example, the laws dealing with PKU are discussed at notes 99-104 and accompanying text *infra*.

[22] For example, the incidence of cystic fibrosis, an autosomal recessive disease, is one in 2500 for United States caucasians. The incidence of PKU is 88 per 10,000,000. H. SUTTON, AN INTRODUCTION TO HUMAN GENETICS 523 (3d ed. 1980). Yet in nearly every state, PKU is the subject of reporting statutes while cystic fibrosis, which cannot be treated or prevented, is rarely required to be reported.

non-specific and grant discretion to a public health authority, legislators must understand that medical genetics, if not in its infancy, is at least in nursery school.[23] While over 2,000 genetic diseases have been identified,[24] many geneticists feel this is the tip of the iceberg. Furthermore, since we all carry between three and five lethal recessive genes,[25] we are all potentially "reportable" as carriers of severe heritable disease. We merely await scientific recognition of our particular defect.

C. Vaccination

Nearly all states have laws authorizing mandatory vaccination, either explicitly or through delegation to local authority which then carries out measures necessary to maintain public health. These state actions often have been challenged in the courts.

Generally courts have supported state power to require vaccination and upheld the constitutionality of laws aimed at protecting public health. In 1905, in *Jacobson v. Massachusetts*,[26] a state law delegated power to a local health authority to require smallpox vaccinations for the populace. This was challenged on the ground that it violated the due process clause of the fourteenth amendment. The Supreme Court rejected the plaintiff's argument that he had been denied liberty without due process of

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[23] The lack of legislative understanding of genetics was illustrated in 1975, when a state legislator drafted a bill calling for compulsory genetic screening for people with a greater than 50% risk of giving birth to a child with serious genetic disease. Under this proposal, virtually no one would be screened because (1) people who are heterozygous for an autosomal recessive disease have a 25% chance of giving birth to a child with that disease, (2) people who suffer from an autosomal dominant disorder have exactly (not greater than) a 50% chance of passing the gene on to offspring, (3) those women who are carriers of an X-linked recessive disorder have exactly (not greater than) a 50% chance of giving birth to a male with the disorder or a female with the trait, and (4) most chromosomal disorders (such as Down's Syndrome) which are not single-gene defects, have a less than 25% chance of occurrence. *See* Cases and Materials on Law and Experimentation on Human Beings, Behavior Modification, and the Genetics 249 (L. Riskin ed. Sept. 1975).

[24] *See generally* McKusick, Mendelian Inheritance in Man: Catalogs of Autosomal Dominant, Autosomal Recessive, and X-Linked Phenotypes (5th ed. 1980).

[25] Morton, Crow & Muller, *An Estimate of Mutational Damage in Man From Data On Consanguinous Marriages*, 42 Proc. Nat'l Acad. Sci. 855 (1956).

[26] 197 U.S. 11 (1905).

law, and placed public health above minimal curtailment of personal liberty. The Court stated that the Constitution did not grant individuals unrestrained liberty, but rather liberty under law for the common good.[27] The *Jacobson* decision established that public health is a primary obligation of the state.[28] As long as statutes are directly related to this obligation, not enforced capriciously, and not over-broad, they are not at variance with the Constitution.

Courts determine the directness of the relationship between public health needs and vaccination statutes through evidence of an actual or threatened epidemic. For example, in *Potts v. Breen*,[29] the Illinois courts struck down a regulation enacted by the State Board of Health because the state did not show the danger or presence of a statewide smallpox epidemic.[30] Increasingly, the threat of an epidemic is seen in terms of prevention.[31] In *Hartman v. May*[32] a municipality acting under Mississippi's general statutory authority "to make regulations to prevent the introduction and spread of contagious or infectious diseases,"[33] passed an ordinance requiring smallpox vaccinations as a condition to attending public schools. Even though there was no smallpox epidemic the court found that the lethal and highly contagious nature of the disease, plus its chronic outbreak in populated areas made the ordinance reasonable and therefore

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[27] *Id.* at 26.

> [The] liberty secured by the Constitution of the United States to every person within its jurisdiction does not impart an absolute right in each person to be, at all times and in all circumstances, wholly free from restraints to which every person is necessarily subject for the common good. On the other basis organized society could not exist with safety to its members.

Id.

[28] The Court said: "The possession and enjoyment of all rights are subject to such reasonable conditions as may be deemed by the governing authority of the country essential to the safety, health, peace, good order, and morals of the community." *Id.* at 26-27 (quoting Crawley v. Christensen, 137 U.S. 86, 89 (1890)).

[29] 167 Ill. 67, 47 N.E. 81 (1897).

[30] *Id.* at 78, 47 N.E. at 85.

[31] Recognizing prevention as a legitimate objective of state action, many states and localities have established vaccination programs as a requirement for school admission. *See, e.g.*, CAL. HEALTH & SAFETY CODE §§ 3380-3390 (West 1979 & Cum. Supp. 1981).

[32] 168 Miss. 477, 151 So. 737 (1934).

[33] *Id.* at 483, 151 So. at 738.

valid.[34]

While courts rarely strike down a vaccination program when evidence of an epidemic is presented, they also rule that an epidemic is not the *sine qua non* when made aware of the dangers of a certain disease. Thus, the pivotal question, based not on scientific data but on public policy, is whether these regulations are clearly arbitrary, capricious, unreasonable, or otherwise unrelated to the health objective.[35]

Genetic disease parallels are difficult to find in the area of vaccination. There is no innoculation to control genetic disease. However, that courts have not required proof of an epidemic to uphold vaccination statutes has interesting implications in the control of genetic disease. Preventive measures for infectious disease may be justified but, as we shall see, preventive measures for genetic disease usually require limitation of reproductive freedom.

D. Quarantine

Quarantine, as a method of disease control, is more restrictive of individual liberty than the measures discussed above. Consequently, legislation regarding quarantine is much more explicit than that for vaccination. Also, most states allow both local and state authorities to initiate a quarantine. For example, California law provides for strict and modified isolation or quarantine and allows state, city, county, or district health officers to initiate such action.[36]

Courts have looked closely at the circumstances surrounding the initiation of a quarantine procedure, for a quarantine potentially restricts not only the diseased, but also "carriers"[37] and even healthy people who reside within a quarantine area. Therefore, courts usually rely on the relative danger presented by the

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[34] *Id.* at 484, 151 So. at 738-39.

[35] *See, e.g.*, State v. Martin & Lipe, 134 Ark. 420, 204 S.W. 622 (1918) (upholding state board of health rule requiring a certificate of smallpox vaccination as condition for school attendance); Zucht v. King, 225 S.W. 267 (Tex. Civ. App. 1920) (upholding city health regulation requiring smallpox vaccination even though there is no epidemic).

[36] CAL. HEALTH & SAFETY CODE §§ 3380-3390 (West 1979 & Cum. Supp. 1981).

[37] *See, e.g.*, People v. Robertson, 302 Ill. 422, 134 N.E. 815 (1922).

disease, and not on its prevalence in the community.[38] Indeed, many quarantine actions have been upheld because there was probable cause to find that the person restricted by the quarantine *may* have been infected.[39] In *People ex rel. Barmore v. Robertson*,[40] the court sustained quarantine of a rooming house proprietress, Jenny Barmore, when a number of her roomers came down with typhoid fever. Barmore was found to be a carrier, although she neither exhibited symptoms nor could relate any history of the disease. The court stressed that its review of quarantine legislation was limited to determining whether the statute was arbitrary, capricious, or oppressive. A reasonable suspicion is an adequate rationale, noted the court, and in the presence of an epidemic, the presumption of validity is always undisturbed.[41] The court also emphasized that "it was not necessary that one be actually sick, as that term is usually applied, in order that the health authorities have the right to restrain [a person's] liberties by quarantine regulations."[42]

It is the courts' job to determine what constitutes an unreasonable quarantine, *i.e.*, one which imposes unreasonable restrictions or curtails liberty without due process of law. While conceding that broad discretion is necessary to determine the proper response to a health emergency, courts step in when control measures result in unnecessary, and therefore unlawful, restrictions upon the individuals affected. For example, at the turn of the century, nine cases of bubonic plague were discovered in San Francisco. In response, the city quarantined twelve square blocks, within which resided over 15,000 persons, the majority of whom were Chinese Americans or Oriental aliens. The United

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[38] *See, e.g., In re* Johnson, 40 Cal. App. 242, 180 P. 644 (2d Dist. 1919).

[39] *See In re* Martin, 83 Cal. App. 2d 164, 188 P. 2d 287 (3d Dist. 1948); State v. Racskowski, 86 Conn. 677, 86 A. 606 (1913); People v. Tait, 261 Ill. 197, 103 N.E. 750 (1913). *But see In re* Shepard, 51 Cal. App. 49, 195 P. 1077 (2d Dist. 1921) ("mere suspicion" is not sufficient).

[40] 302 Ill. 422, 134 N.E. 815 (1922).

[41] *Id.* at 432, 134 N.E. at 819.

[42] *Id.* at 433, 134 N.E. at 819. The court stated:

> One of the most important elements in the administration of health and quarantine regulations is a full measure of common sense. It is not necessary for the health authorities to wait until the person affected with a contagious disease has actually caused others to become sick by contact with him, before he is placed under quarantine.

Id. at 434, 134 N.E. at 820.

States Circuit Court of Appeals for the Ninth Circuit invalidated the action with these words:

> [T]his quarantine cannot be continued, by reason of the fact that it is unreasonable, unjust, and oppressive, and therefore contrary to the laws limiting the police powers of the state and municipality in such matters; and, second, that it is discriminating in its character, and is contrary to the provisions of the 14th Amendment of the Constitution of the United States.[43]

However, the court did permit the San Francisco authorities to "maintain a quarantine around such places as it may have reason to believe are infected by contagious or infectious diseases."[44]

Quarantine, as a preventive measure for genetic disease, presents severe problems. Unlike the transient nature of most infectious disease, a genetic disease is usually a life-long ailment. Because heritable disease cannot be "caught," quarantine seems useless. But, autosomal recessive and X-linked recessive carriers and persons affected with an autosomal dominant disease, and person with certain chromosomal anomolies can pass on genetic disease to offspring. The only effective quarantine would be a ban on procreative liberty. Because we all are carriers of some genetic defects, we could *all* be quarantined.[45]

E. Isolation and Removal

Isolation and removal measures are usually applied to people infected with active cases of tuberculosis, and most states operate special segregated facilities to treat the disease.[46] Similar federal laws provide for the isolation and removal of people afflicted with leprosy.[47] Even though these programs involve severe restriction of personal liberty, there is no longer much litigation over these health statutes.[48]

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[43] Jew Ho v. Williamson, 103 F. 10, 26 (9th Cir. 1900).

[44] *Id.*

[45] Morton, Crow & Muller, *supra* note 25.

[46] All states have laws which either establish special hospitals for treatment of tuberculosis or authorize the state to contract with hospitals for treatment.

[47] "The Surgeon General may provide, by regulation, for the apprehension, detention, treatment, and release of persons being treated by the [United States Public Health] Service for leprosy." 42 U.S.C. § 247e (1980). *See also* 42 C.F.R. § 32.86 to .90 (1980).

[48] *But see* Jones v. Czapkay, 182 Cal. App. 2d 192, 6 Cal. Rptr. 182 (1st Dist. 1960) (suit against city and county health officials alleging negligent failure to

If isolation and removal were applied to victims or carriers of genetic disease, the same unalterable fact would make such measures unfeasible, for we are all genetically flawed.[49] Potentially, we could all be forbidden to mate with certain others with identifiable traits or diseases, genetically stratifying the population.

F. Involuntary Physical Examination

States have had occasional success in forcing physical examination and appropriate treatment against the will of individuals. Usually, these cases have involved venereal disease, and they nearly always have been coupled with criminal prosecution for prostitution. Often, however, quarantine of "houses of ill repute" has been successfully challenged as an abuse of police power. This was the case in *In re Shepherd,*[50] where a California appellate court stated: "more than a mere suspicion that an individual is afflicted with an isolable disease is necessary to give an officer reason to believe that such a person is so afflicted."[51]

Some courts have upheld state authority to force physical examinations of women suspected of having venereal disease. The act of prostitution itself has provided the "reasonable basis" for the state to suspect the presence of the disease.[52] Other courts have disagreed. They have found the state's allegation that illicit sex breeds venereal disease to be unreasonable, and therefore, constitutionally untenable.[53] The use of this type of measure for genetic disease is obvious, particularly in screening for carrier status and in prenatal diagnosis. However, just as its legitimacy in the infectious disease model is highly problematical, so too is its use in prevention of genetic disease.

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enforce quarantine of TB victim from whom plaintiff contracted the disease); District Bd. of T.B. v. City of Lexington, 22 Ky. 7, 12 S.W. 2d 348 (1928) (constitutional challenge to county tax used to finance TB sanatorium).

[49] *See generally* Morton, Crow & Muller, *supra* note 25.

[50] 51 Cal. App. 49, 195 P. 1077 (2d Dist. 1921).

[51] *Id.* at 51, 195 P. at 1077.

[52] *See, e.g.,* People v. Strautz, 386 Ill. 360, 54 N.E. 2d 441 (1944).

[53] In Wragg v. Griffen, 185 Iowa 243, 170 N.W. 400 (1919), the Iowa Supreme Court stated: "[n]owhere does the law provide for deprivation of liberty of persons without due process of law by forcing an examination on mere suspicion." *Id.* at 247-48, 170 N.W. at 401. The court compared forced physical examination to forcing a suspect to incriminate himself. *Id.* at 252, 170 N.W. at 403.

II. State Control of Genetic Disease

State prevention of genetic disease poses certain unique problems that must be examined before statutory controls are proposed. Unlike infectious disease, genetic disease has a universality that should not be ignored. Because every one of us carries lethal (albeit recessive) genes,[54] we are all vulnerable to any restrictions the state may impose to control genetic disease. Furthermore, the natural history of genetic disease mirrors our own life expectancy; in contrast to infectious disease, one does not "recover" from genetic disease.[55]

Both infectious disease and genetic disease are communicable, but there is a difference in the way the two types of diseases spread. Infectious disease is spread horizontally among those already born. Genetic disease, on the other hand, is spread to offspring: it is vertically transmissible. This means that the form of control by the state must necessarily center on human reproduction and limitations on reproductive freedom.

Control of infectious disease focuses on isolating the afflicted from the healthy in order to protect and preserve the healthy group. State control of genetic disease has two targets: (1) To prevent the births of people who are likely to have serious genetic disease, and (2) To cleanse the gene pool of deleterious genes. These two goals are often at odds. For example, "control" of an X-linked recessive disorder such as hemophilia might consist of terminating all male fetuses that are at risk. This would prevent the birth of hemophiliacs, since there is a 50% chance that a male fetus would be affected. But, this method would increase the number of female carriers of the X-linked disorder, since females would have a 50% chance of being carriers.[56]

There are a few genetic diseases, usually inborn errors of metabolism, which can be controlled through diet or drugs. The best-known example of this type of "cure" for a genetic disease

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[54] Morton, Crow & Muller, *supra* note 25.

[55] For the most part, only palliative treatment can be offered. However, if recombination of genes becomes a clinical reality, true treatment and cures may be achieved.

[56] This article deals primarily with control of genetic disease to prevent suffering, rather than to purify the gene pool. For an analysis of how law could affect the genetic load, see Friedman, *Legal Implications of Amniocentesis*, 123 Pa. L. Rev. 92 (1974).

is that for newborns with phenolketonuria (PKU).[57] But, for the most part, control efforts by the state must focus on human reproduction. This places the whole spectrum of control measures in a different constitutional light. The following section examines a number of restrictions the state may impose upon persons at risk of passing on a severe genetic disease. It is followed by a review of the legal issues that might arise from the imposition of such measures. The final passage briefly examines current genetic disease laws in various states.

A. State Control Alternatives

States may take many actions to control infectious disease. State prevention programs have ranged from only slightly restrictive to the highly restrictive measures which still remain for such diseases as leprosy.[58] However, states must justify these actions to the courts, which balance the need for the action against the inroads they make on individual rights protected by the Constitution.[59] For the most part, courts have used the minimum scrutiny test to ascertain whether an action taken to control an infectious disease is legitimate.[60]

For genetic disease, the states also have many options available. At the lowest level of restriction, a state may support an educational program on genetic disease in general, or for a particular genetic disease. By providing information to people at risk of passing on a genetic disease, a state may be exercising effective control.

However, if stricter means are called for, states may set up a reporting scheme which would function as an epidemiological research instrument by counting the number of genetic diseases occurring in a community. Such a reporting statute would be similar to those for infectious disease.[61] There is an obvious danger, however, in the potential for stigmatization that accompanies genetic disease. Therefore, confidentiality and privacy issues are extremely important if registries for genetic diseases are

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[57] *See* H. SUTTON, *supra* note 22, at 256. For a discussion of laws requiring screening of newborns for PKU, see notes 96-105 and accompanying text *infra*.

[58] *See* note 47 and accompanying text *supra*.

[59] *See* notes 26-34, 37-44 and accompanying text *supra*.

[60] *See* note 9 and accompanying text *supra*.

[61] *See* notes 13-18 and accompanying text *supra*.

established.[62]

At the next level of restriction, states may provide or require genetic counseling. This would effectively force information and medical technology upon the prospective parents of the potentially defective child.

More stringent still is government required contraception for couples or individuals whom the state has decided should curtail their reproductive capabilities. At an even higher level of restriction, the state may mandate prenatal diagnosis for those persons at risk of giving birth to a genetically defective child. For example, all women over 35 could be required to undergo amniocentesis screening for Downs Syndrome. Again, the state would be forcing knowledge upon the parent, as well as requiring a physically invasive medical procedure.[63] The step beyond information-forcing, of course, is direct intervention with reproduction. At that level of restriction, abortion might be mandatory if a positive diagnosis of defect is made. Sterilization and euthanasia of defective newborns complete the paradigm of restrictions.

B. Statutory Controls: Constitutional Law Issues

1. Minimum Scrutiny Test

Analysis of the legal underpinnings of genetic disease laws begins with determining whether the laws are voluntary or compulsory. If a law is voluntary and totally non-coercive, and if effective safeguards have been provided for confidentiality and privacy, usually it can be treated in the same way as an infectious disease law — a minimum scrutiny test would suffice.[64] In addition, mandatory screening laws for genetic disease for which there is treatment and cure can also be justified under the minimum scrutiny test.[65]

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[62] For an analysis of the confidentiality issues, see Riskin and Reilly, *Remedies for Improper Disclosure of Genetic Data*, 8 RUT.-CAM. L.J. 480 (1977).

[63] Forced physical examinations for the detection of infectious diseases are discussed at notes 50-53 and accompanying text *supra*.

[64] *See* note 9 and accompanying text *supra*.

[65] The infectious disease analogy is apt because treatable genetic disease acts much the same as infectious disease; i.e., state intervention can cure the disease. Pre-selected birth is not an issue.

2. Strict Scrutiny Test

However, the minimum scrutiny test does not apply to state action that encompasses mandatory abortion, sterilization, euthanasia, or even the less restrictive mandatory reporting and counseling. The state's objective in these actions is preventing selected future life for the protection of future public health, all in the name of the common good. The recent evolution of the constitutional right of privacy[66] has placed genetic disease control beyond the reach of the minimum scrutiny test. Because the state's legitimate interest in protecting citizens' health is extended to future citizens, to those *in utero,* and to those who might exist if a certain sperm and ovum were to join, another set of constitutional standards are employed to justify state control of genetic disease.

The United States Supreme Court has applied a strict scrutiny test when a fundamental constitutional right is infringed.[67] Since vertical transmission of genetic disease necessarily involves sexual intercourse and procreation,[68] strict scrutiny is required for analyzing mandatory genetic disease laws.[69] Strict scrutiny differs from minimum scrutiny in that the statute challenged must not merely be rationally related to the accomplishment of a legitimate state interest; it must be necessary to the accomplishment of a compelling state interest and must employ the least restrictive means to achieve its end.[70]

There are many early cases in which the compelling state interest argument was pivotal,[71] but it was not until 1965 that the

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[66] *See* notes 72-73 and accompanying text *infra.*

[67] *See* notes 69-71 *infra.*

[68] Exceptions are artificial insemination and *in vitro* fertilization.

[69] *See, e.g.,* Graham v. Richardson, 403 U.S. 365 (1971); Loving v. Virginia, 388 U.S. 1 (1967); Hernandez v. Texas, 347 U.S. 475 (1954).

[70] L. TRIBE, *supra* note 9, at 1000. *See also* cases cited at note 69 *supra.*

[71] This theory developed in the 1960's from civil rights cases coming before the Supreme Court. In 1963, in NAACP v. Button, 371 U.S. 415 (1963), the State of Virginia accused the NAACP attorney of soliciting lawsuits which, the state alleged, was improper behavior under state statutes regulating professional conduct. Normally, state action to restrain soliciting would be a proper use of the police power, and the minimum scrutiny test would apply. However, the Supreme Court ruled that Virginia could not impose these restraints because:

> [t]he State's attempt to equate the activities of the NAACP and its lawyers with common law barratry, maintenance and chaperty and to outlaw them accordingly cannot obscure the serious encroach-

Supreme Court established the constitutionally protected right of privacy. In *Griswold v. Connecticut*,[72] the Court struck down a Connecticut statute which proscribed the use of contraceptives, and in doing so prohibited the state from interfering with the privacy surrounding the "intimate relation of husband and wife and their physician's role in one aspect of that relation."[73]

The Court reviewed its previous decisions which centered on the fundamental rights[74] contained in the Bill of Rights and the fourteenth amendment. It concluded that these rights were not static but that they represented principles which could be interpreted to include associated or peripheral rights. The Court reasoned that the Bill of Rights not only had specific guarantees, but, through evolution, had developed "emanations from these guarantees that help give them life and substance."[75] These emanating rights, or "penumbras" surrounding the Bill of Rights, create zones of privacy, particularly in spousal associations. Under the *Griswold* circumstances, these cannot be violated by the state.[76]

> ment worked by . . . [the statute] . . . upon protected freedoms of expression. The decisions of this Court have consistently held that only a compelling State interest in the regulation of a subject within the State's Constitutional power to regulate can justify limiting First Amendment freedoms.

Id. at 438.

In another civil rights case of that era, Bates v. Little Rock, 361 U.S. 516, 524 (1960), the Court reiterated: "where there is a significant encroachment upon personal liberty, the State may prevail only upon showing a subordinating interest which is compelling." And again, in 1963, the Court applied the same strict standard to religious freedom in Shebert v. Verner, 374 U.S. 398 (1963). The Court said:

> We must consider whether some compelling State interest enforced in the eligibility provisions of the South Carolina statute justifies the substantial infringement of appellant's First Amendment right. It is basic that no showing merely of a rational relationship of some colorable State interest would suffice; in this highly sensitive Constitutional area . . . only the gravest abuses, endangering paramount interests give occasions for permissible limitation.

Id. at 406-07 (citing Thomas v. Collins, 323 U.S. 516, 530 (1945)).

[72] 381 U.S. 479 (1965).

[73] *Id.* at 482.

[74] *See* cases cited at note 71 *supra*.

[75] Griswold v. Connecticut, 381 U.S. 479, 484 (1965).

[76] Writing for the majority, Justice Douglas stated:

> The present case . . . concerns a relationship lying within the zone of privacy created by several fundamental Constitutional guaran-

The zone of privacy surrounding the marital relationship was expanded in later cases. *Eisenstadt v. Baird*[77] established the right of single people to buy contraceptives.[78] In 1973, in *Roe v. Wade*,[79] the Court dealt with the issue of privacy in the decision to obtain an abortion. The Supreme Court ruled that the zone of privacy is "broad enough to encompass a woman's decision whether or not to terminate her pregnancy."[80] The Court thus established the zone of privacy around a woman and her physician. During the first trimester, the decision to abort would lie within this zone, and it could not be disturbed by the state.[81] But, after the first trimester, "the State . . . may if it chooses, regulate the abortion procedure in ways that are reasonably related to maternal health."[82] After viability of the fetus, "the State . . . may, if it chooses, regulate and even proscribe, abortion except . . . for the preservation of the life or health of the mother."[83]

Thus, *Roe* stresses that the zones of privacy are *not* inviolate, and gives the parameters of the zone of privacy surrounding the intimate male-female relationship and, of course, procreation. These parameters are not fixed: they expand and contract. The scope of the zone is determined by balancing the individual's right of privacy against a compelling interest of the state which may or may not justify infringement upon that privacy. Already, the federal courts have expanded the concept of the right of privacy to include the privacy of the family.[84] The courts have con-

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> tees . . . . Would we allow the police to search the sacred precincts of marital bedrooms for telltale signs of the use of contraceptives? The very idea is repulsive to the notions of privacy surrounding the marriage relationship.

Id. at 485-86.

[77] 405 U.S. 438 (1972).

[78] Justice Brennan, writing for the Court, stated: "If the right of privacy means anything, it is the right of the *individual*, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child." *Id.* at 453.

[79] 410 U.S. 113 (1973).

[80] *Id.* at 153.

[81] *Id.* at 163.

[82] *Id.*

[83] *Id.* at 164-65.

[84] *See, e.g.*, Merriken v. Cressman, 364 F. Supp. 913 (E.D. Pa. 1973) (junior high school program designed to identify potential drug abusers by means of a questionnaire inquiring into family relationship violates rights of privacy).

tracted the concept to allow state regulation of certain drugs[85] and state proscription of homosexual acts between consenting adults in private.[86] Other abortion decisions following *Roe* have further defined the state's interest in the decision to abort.[87]

This subtle balance may determine the validity of any compulsory genetics laws of the future. State laws to prevent genetic disease must be examined in light of their objectives. To penetrate the individual's zone of privacy, they must be of compelling interest to the state in preserving the health and welfare of its citizenry.

C. State Genetic Disease Statutes

Nearly all states have some type of statute to control genetic disease. Screening laws for treatable inborn errors of metabolism are common, and most are compulsory.[88] Even more comprehensive genetic disease laws are aimed primarily at screening,[89] reporting,[90] counseling,[91] or treating the genetic disease[92] (or carrier status) of the living (whether they are carriers or victims). Actions taken under such laws are voluntary and are protected by strict confidentiality provisions.[93] No genetics laws are specifically geared toward preventing the birth of a defective fetus.[94]

Many state prevention programs for genetic disease have re-

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[85] Whalen v. Roe, 429 U.S. 589 (1977) (enforcement of state narcotics law requiring physician to disclose names of patients prescribed Schedule II drugs does not violate privacy rights).

[86] Doe v. Commonwealth's Attorney, 403 F. Supp. 1199 (E.D. Va. 1975), *aff'd*, 425 U.S. 901 (1976) (constitutionality of Virginia's sodomy statute upheld in general and as applied to private acts of consenting homosexual adults). *But see* State v. Bateman, 25 Ariz. App. 1 (1975).

[87] H.L. v. Matheson, 450 U.S. 398 (1981); Williams v. Zbaraz, 448 U.S. 358 (1980); Harris v. McRae, 448 U.S. 297 (1980); Bellotti v. Baird, 443 U.S. 622 (1979); Williams v. Zbaraz, 442 U.S. 1309 (1979); Colautti v. Franklin, 439 U.S. 379 (1979); Beal v. Doe, 432 U.S. 438 (1977); Maher v. Roe, 432 U.S. 464 (1977); Poelker v. Doe, 432 U.S. 519 (1977); Planned Parenthood of Central Mo. v. Danforth, 428 U.S. 52 (1976); Doe v. Bolton, 410 U.S. 179 (1973).

[88] *See* notes 96-104 and accompanying text *infra*.

[89] *See* notes 99-104, 109-110 *infra*.

[90] *See* note 95 *infra*.

[91] *See, e.g.*, notes 120, 125 and accompanying text *infra*.

[92] *See, e.g.*, note 120 and accompanying text *infra*.

[93] *See* notes 113, 119 and accompanying text *infra*.

[94] A possible exception is the Alabama statute discussed at notes 125-29 and accompanying text *infra*.

porting requirements similar to those for infectious disease. A certain amount of "genetic disease reporting" is done on a very gross level in the form of birth certificate information, which requires registry of congenital birth defects.[95]

The most common genetic disease statutes are those requiring screening of newborns for phenylketonuria (PKU). Phenylketonuria is an autosomal recessive disease in which affected infants lack an enzyme, phenylalanine hydroxylase, a condition that eventually causes usually severe mental retardation.[96] When PKU is diagnosed in an infant, a special diet low in phenylalinine provides a "cure".[97] Treatment must be introduced in infancy to be effective.[98]

PKU statutes, passed in the early and mid-60's, exist in 44 states.[99] Many of them are broad, requiring diagnostic tests for

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[95] *See, e.g.*, CAL. HEALTH & SAFETY CODE § 10125 (West Cum. Supp. 1981); CONN. GEN. STAT. ANN. §§ 19-21 (West Cum. Supp. 1981); MASS. GEN. LAWS ANN. ch. 111, § 67E (West 1971); N.D. CENT. CODE § 59-20-02 (1974); WIS. STAT. ANN. § 69.32 (West 1965 & Cum. Supp. 1981).

[96] Phenylalanine hydroxlase is an enzyme which, in normal persons, changes excess phenylalanine into tyrosine. As phenylalanine levels in phenylketonic infants rise in the blood, other reactions take the place of tyrosine production. But the end result is mental retardation. H. SUTTON, *supra* note 22, at 254.

[97] Total elimination of phenylaline is not possible or desirable since it is necessary in building proteins. *Id.* at 256.

[98] *Id.*

[99] ALA. CODE § 22-20-3 (Supp. 1981); ALASKA STAT. § 18.15.200 (1974); ARIZ. REV. STAT. ANN. § 36-694B (Supp. 1981); ARK. STAT. ANN. §§ 82-265 to -628 (1976 & Supp. 1981); CAL. HEALTH & SAFETY CODE §§ 309 to 309.5 (West Cum. Supp. 1981); COLO. REV. STAT. §§ 25-4-801 to -804 (1973); CONN. GEN. STAT. ANN. § 19-21b (West 1977 & Supp. 1981); FLA. STAT. ANN. § 383.14 (West 1973 & Supp. 1981); GA. CODE ANN. §§ 88-1201.1 to -1201.3 (1979); HAWAII REV. STAT. § 333-1 (1976); IDAHO CODE §§ 39-909 to -912 (1977); ILL. ANN. STAT. ch. 111 ½, §§ 4903 to 4905 (Smith-Hurd Supp. 1981); IND. CODE ANN. §§ 16-8-6-1 to -7 (Burns Supp. 1979); IOWA CODE ANN. § 135.31 (West 1972); KAN. STAT. ANN. §§ 65-180 to -183 (1980); LA. REV. STAT. ANN. §§ 40:1299 to :1299.4 (West Cum. Supp. 1981); ME. REV. STAT. ANN. tit. 22, § 1522 (1980); MD. ANN. CODE art. 43, §§ 814 to 821 (1980); MASS. GEN. LAWS ANN. ch. 111, § 110A (West Cum. Supp. 1981); MICH. COMP. LAWS ANN. §§ 333.5431 to .5439 (1980); MINN. STAT. ANN. § 144.125 (West Cum. Supp. 1981); MISS. CODE ANN. §§ 41-21-201 to -203 (1981); MO. ANN. STAT. § 210.065 (Vernon Supp. 1981); MONT. CODE ANN. §§ 50-19-201 to -204 (1979); NEB. REV. STAT. §§ 71-604.01 to .04 (1976); NEV. REV. STAT. § 442.115 (1979); N.H. REV. STAT. ANN. §§ 132:10-a to :10-c (1978); N.J. STAT. ANN. §§ 26:2-84 to -85 (West Cum. Supp. 1981); N.M. STAT. ANN. § 24-1-6 (1981); N.Y. PUB. HEALTH LAW § 2500a (McKinney 1977); N.D. CENT. CODE §§ 25-17-01 to -04 (1978); OHIO REV. CODE ANN. §§ 3701.501 to

several other inborn errors of metabolism which cause mental retardation.[100] Although these laws are mandatory, 28 states provide statutory exemptions for people who object to the tests on religious grounds.[101] Seven other states allow exemptions to par-

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.502 (Page Supp. 1981); OKLA. STAT. ANN. tit. 63, § 1-533 (West 1973); OR. REV. STAT. §§ 433.285 to .295 (1981); PA. STAT. ANN. tit. 35, § 621 (Purdon 1977); R.I. GEN. LAWS § 23-13-12 (1979); S.C. CODE ANN. § 44-37-30 (Law. Co-op. Supp. 1981); S.D. COMP. LAWS ANN. §§ 34-24-16 to -25 (1977); TENN. CODE ANN. §§ 53-624 to -633 (1977 & Supp. 1980); TEX. REV. CIV. STAT. ANN. art. 4447e (Vernon Supp. 1981); UTAH CODE ANN. § 26-17-21 (1976); VA. CODE §§ 32.1-65 to -67 (1979 & Supp. 1981); WASH. REV. CODE ANN. §§ 70.83.010 to .060 (1975 & Supp. 1981); W. VA. CODE §§ 16-22-1 to -6 (1979); WIS. STAT. ANN. § 146.02 (West Supp. 1981); WYO. STAT. §§ 35-4-801 to -802 (Supp. 1981).

[100] *See, e.g.*, ALA. CODE § 22-20-3(a) (Supp. 1981); ARIZ. REV. STAT. ANN. § 36-694B (Supp. 1981); ARK. STAT. ANN. §§ 82-625 to -626 (Supp. 1981); CAL. HEALTH & SAFETY CODE § 309 (West Cum. Supp. 1981); COLO. REV. STAT. §§ 25-4-801 to -802 (1973); CONN. GEN. STAT. ANN. § 19-21b (West Cum. Supp. 1981); FLA. STAT. ANN. § 383.14 (West Cum. Supp. 1981); GA. CODE ANN. §§ 88-1201.1 to -1201.2 (1979); IDAHO CODE §§ 39-909 to -912 (1977); ILL. ANN. STAT. ch. 111 ½, § 4903 (Smith-Hurd Supp. 1980); IND. CODE ANN. § 16-8-6-1 (Burns Supp. 1979); KAN. STAT. ANN. § 65-180 (1980); LA. REV. STAT. ANN. §§ 40:1299 to :1299.4 (West Cum. Supp. 1981); ME. REV. STAT. ANN. tit. 22, § 1522 (1980); MD. ANN. CODE art. 43, §§ 814 to 821 (1980); MICH. COMP. LAWS ANN. §§ 333.5411 (1980); MINN. STAT. ANN. § 144.125 (West Cum. Supp. 1981) Mo. ANN. STAT. § 210.065 (Vernon Supp. 1981); MONT. CODE ANN. § 50-19-203 (1979); NEB. REV. STAT. §§ 71-604.01 to 604.03 (Cum. Supp. 1980); NEV. REV. STAT. § 442.115 (1979); N.M. STAT. ANN. § 24-1-6 (1981); N.Y. PUB. HEALTH LAW § 2500a (McKinney 1977); N.D. CENT. CODE § 25-17-01 (1978); OHIO REV. CODE ANN. § 3701.50.1 (Page Supp. 1980); OKLA. STAT. ANN. tit. 63, § 1-533 (West 1973); OR. REV. STAT. § 433.285 (1981); PA. STAT. ANN. tit. 35, § 621 (Purdon 1977); S.C. CODE ANN. § 44-37-30 (Law. Co-op. Supp. 1981); S.D. COMP. LAWS ANN. §§ 34-24-17 & -22 (1977); TENN. CODE ANN. §§ 53-624 to -633 (1977 & Supp. 1980); TEX. REV. CIV. STAT. ANN. art. 4447e (Vernon Supp. 1981); UTAH CODE ANN. § 26-17-21 (1976); WASH. REV. CODE ANN. § 70.83.020 (Supp. 1981); W. VA. CODE § 16-22-2 (1979); WIS. STAT. ANN. § 146.02 (West Cum. Supp. 1981); WYO. STAT. § 35-4-801 to -802 (Supp. 1981).

[101] ALA. CODE § 22-20-3(a) (Supp. 1981); ARK. STAT. ANN. § 82-627 (1976); CAL. HEALTH & SAFETY CODE § 309 (West Cum. Supp. 1981); COLO. REV. STAT. § 25-4-804 (1973); CONN. GEN. STAT. ANN. § 19-21b (West 1977); GA. CODE ANN. § 88-1201.1(a) (1979); HAWAII REV. STATS. § 333-10 (1976); IDAHO CODE §§ 39-909 to -912 (1977); ILL. ANN. STAT. ch. 111 ½, § 4905 (Smith-Hurd Supp. 1980); IND. CODE ANN. § 16-8-6-1 (Burns Supp. 1979); KAN. STAT. ANN. § 65-182 (1980); ME. REV. STAT. ANN. tit. 22, § 1522 (1980); MINN. STAT. ANN. § 144.125 (West Cum. Supp. 1981); MO. ANN. STAT. § 210.065(4) (Vernon Supp. 1981); NEB. REV. STAT. § 71-604.01 (Cum. Supp. 1980); N.J. STAT. ANN. § 26:2-84 (West Cum. Supp. 1981); N.Y. PUB. HEALTH LAW § 2500a (McKinney 1977); N.D. CENT. CODE § 25-17-04 (1978); OHIO REV. CODE ANN. § 3701.50.1(B) (Page

ents who object for any reason.[102] Most laws do not prescribe or require treatment; however, 17 states track infants with positive tests, and provide for necessary medical care where it is otherwise unavailable or too expensive.[103] In only nine states does the law specifically make it a misdemeanor for a physician or other person to fail to test a child.[104] The diagnostic test for PKU is not severely invasive (it consists of drawing blood), nor are the tests expensive (they are usually subsidized by the state). Therefore, there has been very little opposition to such laws.

Laws regulating PKU and kindred inborn metabolic errors can be viewed for constitutional purposes in the same way as infectious disease laws. Minimally invasive tests, availability of treatment, and treatment of the living without curtailment of

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Supp. 1980); OKLA. STAT. ANN. tit. 63, § 1-534 (West 1973); PA. STAT. ANN. tit. 35, § 621 (Purdon 1977); R.I. GEN. LAWS § 23-13-12 (1979); S.C. CODE ANN. § 44-37-30 (Law. Co-op. Supp. 1981); S.D. COMP. LAWS ANN. §§ 34-24-17 (1977); TENN. CODE ANN. §§ 53-624 to -633 (1977 & Supp. 1980); TEX. REV. CIV. STAT. ANN. art. 4447e (Vernon Supp. 1981); VA. CODE § 32.1-65 (1979); WASH. REV. CODE ANN. § 70.83.020 (Supp. 1981); WIS. STAT. ANN. § 146.02(3) (West Cum. Supp. 1981).

Some states may allow exemption on the basis of religious beliefs through regulations. Other states, such as Massachusetts, have statutory language authorizing a general program but, because of the voluntary nature of these screening programs to detect genetically-linked diseases, any PKU program under its aegis would provide exemption for those objecting on religious grounds.

[102] FLA. STAT. ANN. § 383.14 (West 1933 & Cum. Supp. 1981); LA. REV. STAT. ANN. §§ 40:1299 to :1299.4 (West Cum. Supp. 1981); MISS. CODE ANN. § 41-21-203 (Supp. 1980); NEV. REV. STAT. § 442.115 (1979); N.H. REV. STAT. ANN. § 132:10-c (1977); N.M. STAT. ANN. § 24-1-6(A) (1978); WYO. STAT. §§ 35-4-801 to -802 (Supp. 1981).

[103] ALA. CODE § 22-20-3(b) (Supp. 1979); ALASKA STAT. § 18.15.200(d) (1974); ARK. STAT. ANN. § 82-626 (Supp. 1981); FLA. STAT. ANN. § 383.14 (West Cum. Supp. 1981); GA. CODE ANN. § 88-1201.1(b) (1979); ILL. ANN. STAT. ch. 111 ½, § 4904(c) (Smith-Hurd Supp. 1981); KAN. STAT. ANN. § 65-180(d) (1980); LA. REV. STAT. ANN. §§ 40:1299 to :1299.4 (West Cum. Supp. 1981); MISS. CODE ANN. § 41-21-203 (Supp. 1980) N.D. CENT. CODE § 25-17-03 81978); S.D. COMP. LAWS ANN. §§ 34-24-24 to -25 (1977); TEX. REV. CIV. STAT. ANN. art. 4447e (Vernon Supp. 1981); VA. CODE § 32.1-67 (Supp. 1981); WASH. REV. CODE ANN. §§ 70.83.040 to .050 (Supp. 1981); W. VA. CODE § 16-22-3 (1979).

[104] ALASKA STAT. § 18.15.200(f) (1974); IDAHO CODE §§ 39-909 to -912 (1977); ILL. ANN. STAT. ch 111 ½, § 4904(e) (Smith-Hurd Supp. 1981); MICH. COMP. LAWS ANN. § 333.5431 (1980); MO. ANN. STAT. § 210.065(5) (Vernon Supp. 1981); NEB. REV. STAT. § 71-613 (Supp. 1980); S.C. CODE ANN. § 44-37-30 (Law. Co-op. Supp. 1981); TENN CODE ANN. §§ 53-624 to -633 (1977 & Supp. 1980); W. VA. CODE § 16-22-4 (1979).

reproductive choices, places these mandatory laws within the purview of minimum scrutiny. Certainly, states can show a direct and rational relationship between the screening and public health. No infringement of fundamental rights is involved.

No easy acceptance has greeted screening statutes for sickle-cell anemia however. This autosomal recessive disease causes severe anemia as red blood cells are destroyed by abnormal "sickling" of the hemoglobin protein.[105] Those with sickle-cell anemia have a significantly shortened life expectancy. Frequency of the disease among American blacks is high.[106]

Widespread ignorance about the disease on the part of legislators,[107] obvious problems of drafting legislation aimed at an historical "suspect classification," and screening tests conjoined with premarital serological tests for venereal disease[108] have caused visceral feelings of fear and suspicion, and have contributed to the repeal of most mandatory sickle-cell screening laws.[109] However, 21 states maintain sickle-cell laws.[110] Of these,

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[105] H. SUTTON, *supra* note 22, at 154-55.

[106] In the United States, the disease affects one in 500 infants born to black parents who are heterozygous for the trait. *Id.* at 238-39.

[107] *See, e.g.*, VA. CODE § 32-112.19 (1950)(repealed 1973), which required screening for sickle-cell anemia and sickle-cell trait to be carried out on all inmates of state prisons and mental institutions, thus linking this genetic disease with anti-social, criminal, or retarded behavior.

[108] ALASKA STAT. §§ 25.05.101 to .181 (1977) (provides for premarital screening for heritable diseases; compulsory unless religious objections raised or physician unavailable); ARIZ. REV. STAT. ANN. §§ 36-797.40 to -797.43 (1974 & Supp. 1981) (state may provide premarital screening *with consent*); ILL. ANN. STAT. ch. 40, §§ 204-05 (Smith-Hurd 1980) (provides that premarital testing may be given when physician deems appropriate unless religious objections raised); IND. CODE ANN. § 31-1-7 (Burns 1980) (screening tests included in premarital exam unless religious objections raised); IOWA CODE ANN. §§ 141.1 to .6 (West Cum. Supp. 1981) (screening done on a *voluntary* basis); KY. REV. STAT. § 402.310-40 (Supp. 1980) (screening tests to be done with premarital examination).

[109] Only three states maintain involuntary sickle-cell screening laws. Indiana and Massachusetts require screening before admission to school. IND. CODE ANN. § 20-8.1-7-14 (Burns 1975); MASS. GEN. LAWS ANN. ch. 76, § 15A (West Cum. Supp. 1981). Kentucky law states that a sickle-cell screening test shall be administered with premarital examination. KY. REV. STAT. § 402.310-40 (Supp. 1980). Seven states have laws which allow religious (but not ethical or moral) objections to be raised prior to sickle-cell screening tests. *See* note 115 *infra*.

[110] ARIZ. REV. STAT. ANN. §§ 36-797.41 to -797.43 (1974 & Supp. 1981); CAL. HEALTH & SAFETY CODE §§ 320.5 to 324.5, 325 to 327 (West 1979 & Cum. Supp. 1981); COLO. REV. STAT. §§ 23-21-201 to 204 (1973 & Supp. 1981); CONN. GEN.

three provide only for research, education, or financial support for diagnosis and treatment.[111] Of the 18 state screening laws (both premarital and school screening programs), eight are voluntary,[112] and five have confidentiality provisions.[113] Nine of the statutes are to some degree involuntary,[114] seven of these provide only for religious objections.[115]

In addition to screening laws, many states have passed broad-based laws to support research into causes of genetic disease,

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STAT. ANN. §§ 10-206 to -210 (West Cum. Supp. 1981); D.C. CODE ENCYCL. § 32-322 (West Cum. Supp. 1978); GA. CODE ANN. §§ 88-1201.1 to -1202.3 (1979); ILL. ANN. STAT. ch. 40, §§ 204 to 205 (Smith-Hurd 1980); IND. CODE ANN. §§ 20-8.1-7-10 to -11, & -14 (Burns 1975 & Supp. 1979), IND. CODE ANN. §§ 16-2-5-1 to -9 (Burns Supp. 1979) and IND. CODE ANN. § 31-1-1-7 (Burns 1979); IOWA CODE ANN. §§ 141.1 to .6 (West Cum. Supp. 1981); KAN. STAT. ANN. §§ 65-1,105 to 1,106 (1980); KY. REV. STAT. §§ 402.310 to .340 (Supp. 1980); LA. REV. STAT. ANN. §§ 40:1299 to :1299.4 (West 1977) and LA. REV. STAT. ANN. § 17:170 (West Cum. Supp. 1981); MASS. GEN. LAWS ANN. ch. 76, §§ 15A to 15B (West Cum. Supp. 1981); MISS. CODE ANN. §§ 41-21-1 to -5 (Supp. 1980); N.J. STAT. ANN. §§ 62:2-110 to -111 (West Cum. Supp. 1981) and N.J. STAT. ANN. § 9:14B-1 (West 1976); N.M. STAT. ANN. § 24-3-1 (1979); N.Y. EDUC. LAW §§ 903 to 904 (McKinney Supp. 1981); N.C. GEN. STAT. §§ 143B-188 to -196 (1978); OHIO REV. CODE ANN. § 3701.13.1 (Page 1980); S.C. CODE ANN. § 44-33-10 (Law. Co-op. 1976); VA. CODE §§ 32.1-68 to -69 (1979).

[111] COLO. REV. STAT. §§ 23-21-203 to -204 (1973 & Supp. 1981); N.J. STAT. ANN. § 9:14B-1 (West 1976); OHIO REV. CODE ANN. § 3701.13.1 (Page 1980).

[112] ARIZ. REV. STAT. ANN. § 36-797.42c (1974 & Supp. 1981); D.C. CODE ENCYCL. § 32-322 (West Cum. Supp. 1978); IOWA CODE ANN. § 141.2 (West Cum. Supp. 1981); KAN. STAT. ANN. § 65-1,105(a) (1980); LA. REV. STAT. ANN. § 17:170 (West Cum. Supp. 1981); N.C. GEN. STAT. § 143B-196 (1978); S.C. CODE ANN. § 44-33-10 (Law. Co-op. 1976); VA. CODE § 32.1-68A (1979).

[113] CONN. GEN. STAT. ANN. § 10-209 (West Cum. Supp. 1981); IOWA CODE ANN. § 141.5 (West Cum. Supp. 1981); KAN. STAT. ANN. §§ 65-1,106 (1980); MASS. GEN. LAWS ANN. ch. 76, 15B (West Cum. Supp. 1981); VA. CODE § 32.1-69 (1979).

[114] ALASKA STAT. §§ 25.05.101 to .181 (1977); CAL. HEALTH & SAFETY CODE § 325 (West 1979); CONN. GEN. STAT. ANN. § 10-206 (West Cum. Supp. 1981); GA. CODE ANN. § 88-1201.1(a) (1979); ILL. ANN. STAT. ch. 40, § 204 (Smith-Hurd 1980); IND. CODE ANN. §§ 16-2-5-1 to -9 (Burns Supp. 1980); KY. REV. STAT. §§ 402.310 to .340 (Supp. 1980); MASS. GEN. LAWS ANN. ch. 76, § 15A (West Cum. Supp. 1981); N.Y. EDUC. LAW § 903 (McKinney Supp. 1981).

[115] ALASKA STAT. § 25.05.181 (1977); CAL. HEALTH & SAFETY CODE § 325 (West 1979); CONN. GEN. STAT. ANN. § 10208 (West Cum. Supp. 1981); GA. CODE ANN. § 88-1201.1(a) (1979); ILL. ANN. STAT. ch. 40, § 205 (Smith-Hurd 1980); IND. CODE ANN. § 31-1-1-7(f) (Burns 1980) (for premarital test only); N.Y. EDUC. LAW § 903 (McKinney Supp. 1981).

and to offer prevention programs, all of which are voluntary.[116] The most noteworthy of these laws is that of Maryland. In 1973, the Maryland legislature created the Commission on Hereditary Disorders,[117] and empowered it to:

> 1. Establish and promulgate rules, regulations, and standards for the detection and management of hereditary disorders in the State of Maryland;
> 2. Gather and disseminate information to further the public's understanding of hereditary disorders;
> 3. Establish systems for recording information obtained in programs regulated by the Commission;
> 4. Reevaluate on a continuous basis the need for and efficacy of state programs on hereditary disorders; and
> 5. Investigate unjustified discrimination resulting from identification as a carrier of a hereditary disorder, and make recommendations as the commission deems necessary to end such unjustified discrimination.[118]

Any programs originated by the Commission are to be voluntary, and information gathered is to be strictly confidential.[119] The enabling legislation encompasses screening, counseling, and other methods for "treating" genetic disorders,[120] as well as protecting the participants and the data generated by them. In addition, the non-compulsory, non-coercive aspects of the law are precisely drawn. No test may be performed on any individual over 18 if any objection is raised at all, or on any individual under 18 or on any incompetent over the objection of parents or guardian. No test may be performed unless such individual, parent, or guardian is fully informed of the purpose for testing for hereditary disorders and the carrier state of hereditary disorders, and is given a reasonable opportunity to object to the testing.[121] Further, no program may require mandatory participation, restrict childbearing, or be a prerequisite to participation

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[116] ALA. CODE §§ 22-10A-1 to -3 (Supp. 1981); CAL. HEALTH & SAFETY CODE §§ 309 to 309.5 (West Cum. Supp. 1981); GA. CODE ANN. §§ 88-1201 to 1201.3 (1979); MD. ANN. CODE art. 43, §§ 814 to 821 (1980); MASS. GEN. LAWS ANN. ch. 76, § 15B (West Cum. Supp. 1981); MICH. COMP. LAWS ANN. §§ 333.5401 to .5439 (1980); MINN. STAT. ANN. §§ 144.91 to .94 (West 1970 & Cum. Supp. 1981); N.Y. PUB. HEALTH LAW §§ 2730 to 2733 (McKinney 1977); N.C. GEN. STAT. §§ 143B-188 to -196 (1978); VA. CODE §§ 32.1-68 to .1-69 (1979).

[117] MD. ANN. CODE art. 43, §§ 814 to 821 (1980).

[118] *Id.* § 817(a).

[119] *Id.* §814(j), § 818(c), (j).

[120] *Id.* § 817(b).

[121] *Id.* § 818(e).

in any other service program.[122] Finally, counseling services for hereditary disorders are to be available to anyone involved in the screening program. The counseling is to be non-directive, emphasizing education of the client. It may not require restriction of childbearing.[123]

For the most part, current genetic disease laws are uniformly voluntary, non-directive, and non-coercive.[124] However, one state has gone beyond the other programs. In May, 1978, an act became effective that expanded the genetics services offered by the state medical schools of Alabama. The stated purpose was to "encourage prevention of birth defects and mental retardation through education, genetic counseling, and amniocentesis when applicable."[125] To carry out these policies, the state medical schools were charged with expanding their genetic services, offering education for physicians and the public, counseling and prenatal diagnosis.[126] For the first time, a state statute indirectly coupled abortion with prevention of genetic disease. The statute mandates that "prenatal diagnosis shall be offered to those . . . meeting criteria for eligibility."[127] Those eligible include: pregnant women over 35, one parent with a translocation, both parents if they are carriers of an autosomal recessive disease detectable *in utero,* parents of a previous child with Down's Syndrome or other chromosomal anomaly, or a neural tube defect, and women who are carriers of an X-linked disorder.[128]

Through this law, Alabama has implicitly endorsed the only "cure" for genetic disease, i.e., preventing birth of those destined to suffer. While participation is strictly voluntary,[129] state policy seems to be to facilitate prevention of the birth of genetically diseased infants. For example, in the case of X-linked recessive

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[122] *Id.* § 818(f).

[123] *Id.* § 818(g).

[124] Beyond the Maryland approach are other state statutes aimed at specific disorders, such as hemophilia or cystic fibrosis. Most offer only financial assistance and rehabilitative facilities from the state. *See, e.g.,* OHIO REV. CODE ANN. § 3701.02.3 (Page 1980) (provides diagnostic treatment and support services to children with cystic fibrosis, sickle-cell anemia or other organic defect); *id.* § 3701.14.4 (creates program to care for persons with hemophilia).

[125] ALA. CODE § 22-10A-1 (Supp. 1981).

[126] *Id.* § 22-10A-2.

[127] *Id.*

[128] *Id.*

[129] *Id.* § 22-10A-3.

disorders, prenatal diagnosis would probably be aimed at sex selection since at present no X-linked diseases can be diagnosed through amniocentesis, and, therefore, the preventive measure would be the termination of all male fetuses (which run a one in two chance of being affected by the disorder).[130] Females, of course, would only run the risk of being carriers.

The laws reviewed above have been completely voluntary, with the exception of some of the screening programs.[131] Thus, the role of the states is to offer or underwrite a service, not to enforce a policy. Furthermore, most statutes are broadly drawn and offer counseling and screening measures. These usually go unchallenged in the courts, but if challenged, their voluntary nature places them squarely under the aegis of minimum scrutiny.[132] No laws address prevention in direct terms by requiring at-risk couples to limit procreation. To do so would place the statute under strict scrutiny and require the state to demonstrate a compelling interest and show it was using the least restrictive means to accomplish its goal.[133]

There may be some circumstances under which states would be justified in mandating specific measures to ensure that certain individuals do not inflict severe genetic disease on their offspring. States and, ultimately, the courts will have to balance the degree of risk, the severity of the disease, the age of onset, alternative "treatments," cost of non-treatment (both financial and emotional), and the appropriate points of intervention.

D. The Strict Scrutiny Test and Genetic Disease Laws

Defining compelling state interest in terms of preventing genetic disease poses a dilemma. Is the interest defined in terms of numbers of persons affected, severity of the disease, or economic costs to the state and society? To weigh only the economic burden is clearly not satisfactory. Indeed, courts have held that when an asserted compelling state interest is purely economic, the fundamental right of the individual is preeminent.[134] It may

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[130] *See* H. SUTTON, *supra* note 22, at 19-20.

[131] *See, e.g.*, notes 99-104 and accompanying text *supra* for a discussion of screening laws for PKU.

[132] Jacobson v. Massachusetts, 197 U.S. 11 (1905). *Jacobson* is discussed at text accompanying note 26 *supra*.

[133] *See* notes 58-70 and accompanying text *supra*.

[134] Montgomery v. Board of Retirement, 33 Cal. App. 3d 447, 453, 109 Cal.

in fact become necessary to develop a calculus of all pertinent social and economic factors, so that states may assert an interest sufficiently compelling to legitimize deep incursions into an individual's procreational privacy to further the health and good of the whole populus.

In *Roe,* the Supreme Court sanctioned state interference with the zone of privacy only at the time of fetal viability, and only to preserve and protect potential life.[135] Consequently, it may follow that courts will justify violating the privacy zone to mandate genetic counseling, prenatal diagnosis, or other procedures to protect the future life of the fetus before viability. If, however, states go further and mandate abortion or sterilization, the rationale backing the compelling state interest — preserving potential life — is underminded. Eugenic measures of this type envision not protection of the individual potential life but, hearkening back to the infectious disease law objectives, protection and enhancement of a future public. We may argue that the state has a compelling interest sufficient to mandate a second trimester abortion. Such an argument might be sustained on the basis of protecting future generations, or safeguarding society through perpetuation and maintenance of a healthy gene pool. If, for example, the state could demonstrate that society was faced with an epidemic of severe genetic disorders resulting from mutagenic agents released into the atmosphere as industrial pollutants, then the state, in preserving its future, might be able to show a sufficiently compelling interest to force abortion of those fetuses affected by the mutagens, assuming such identification was technologically possible.

If, however, we wish to selectively mandate abortion to prevent the birth of a defective fetus in order to prevent its suffering, we will have a difficult time coming up with a compelling state interest to justify interference. *Roe* states that a fetus is not a person who merits fourteenth amendment protection;[136] that the zone of privacy surrounding the relational doctor/patient decision whether to abort must remain inviolate, un-

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Rptr. 181, 185 (5th Dist. 173) (quoting Goldberg v. Kelly, 397 U.S. 254 (1970)): "[I]n a constitutional context involving basic rights, the preservation of moneys is not of primary significance."

[135] Roe v. Wade, 410 U.S. 113, 164-65 (1973). *See* notes 79-83 and accompanying text *supra.*

[136] Roe v. Wade, 410 U.S. 113, 161-62 (1973).

touched by state interference during the first trimester; that in the second trimester, the privacy zone protecting the decision can be infringed by the state before fetal viability only to protect maternal health.[137]

If we base our compelling state interest on preventing the defective fetus from being born alive, we are giving legal status to a non-person, and making that status preeminent to that of the mother. The Supreme Court has already ruled that states cannot interfere with the abortion decision by imposing the requirement of spousal, or in the case of a minor, parental consent.[138] Is there then justification for the state's interference with this decision through imposition of a fetal interest in *not* being born?[139] During the first trimester, and largely during the second trimester, the decision can be made free from state regulation to discard or give birth to normal *or defective* fetuses. The Supreme Court in *Roe* was not addressing a question of the quality of life; it was merely addressing the question of abortion without specifying the type of fetus to be aborted.

We may assert that a compelling state interest exists for protecting the general health, rather than individual (fetal) health. And we need look no further than state compulsory sterilization laws to find ample judicial precedent for state prevention of life in the name of the common good.[140] In 1927, a Virginia law of

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[137] *Id.* at 163.

[138] Bellotti v. Baird, 443 U.S. 622 (1979); Planned Parenthood of Central Missouri v. Danforth, 428 U.S. 52 (1976); H.L. v. Matheson, 450 U.S. 398 (1981).

[139] If the state imposes a limitation on this decision in the name of preventing births of defective fetuses, the zone of privacy may be pierced, and the private right to decide may be abrogated. Also, those who consider abortion to be homicide may demand that the interest of the normal fetus is similarly represented by state action.

[140] State laws permitting sterilization for the mentally ill or mentally retarded have existed for over half a century. At least fourteen such statutes survive today. *See, e.g.*, ARK. STAT. ANN. §§ 59-501 to -502 (1971); DEL. CODE ANN. tit. 16, §§ 5701 to 5705 (1975); GA. CODE ANN. §§ 84-931 to -936 (1979); IDAHO CODE §§ 39-3901 to -3910 (1977); ME. REV. STAT. ANN. tit. 34, §§ 2461 to 2468 (1978); MISS. CODE ANN. §§ 41-45-1 to -19 (1972); N.C. GEN. STAT. §§ 35-36 to -45 (1976 & Supp. 1981); OKLA. STAT. ANN. §§ 43A-341 to -346 (West 1979); OR. REV. STAT. §§ 436.010 to .150 (1973); S.C. CODE ANN. §§ 44-47-10 to -100 (Law. Co-op. 1976); UTAH CODE ANN. §§ 64-10-1 to -13 (1953); VT. STAT. ANN. tit. 18, §§ 801 to 8704 (1968); WASH. REV. CODE ANN. § 9.92.100 (1977); W. VA. CODE §§ 27-16-1 to -5 (1980). Four states maintain voluntary sterilization laws: COLO. REV. STAT. §§ 27-10.5-128 to -132 (Supp. 1980); MONT. CODE

this type was upheld by the Supreme Court. In *Buck v. Bell*,[141] Chief Justice Holmes reasoned that such a procedure would be beneficial to both the patient and the community because it would allow the patient to return to society, but relieve society of the burden of caring for unwanted, uncared for, and possibly mentally retarded offspring.[142] That case still stands, and later cases, in upholding the constitutionality of involuntary sterilization laws, rely on its precedent. Typical of these cases is *Cook v. State*,[143] in which the Oregon court of appeals upheld the State Board of Protection's decision to sterilize a 17-year old woman with a history of chronic aggressive hostility because ". . . procreation by the examinee would produce a child or children . . . who would become neglected or dependent children as a result of the parents' inability by reason of mental illness or mental retardation to provide adequate care."[144]

Other compulsory sterilization statutes, however, have been found to be unconstitutional on procedural due process grounds[145] or because of equal protection deficiencies in relation to the imprisoned or the institutionalized.[146] Until 1976, post-*Roe* challenges to compulsory sterilization laws, regardless of outcome, ignored the concept of constitutional privacy rights surrounding procreation. Left unanswered was the question of whether the state possessed a sufficiently compelling interest to prevent the birth of infants who may be mentally defective, and who, in any case, would become the wards of the state because their parents were mentally incapable of caring for them.

ANN. §§ 53-23-101 to -105 (1979); N.J. STAT. ANN. § 30:6D-5 (West 1981); OHIO REV. CODE ANN. § 5123.86 (Page Supp. 1981).

[141] 274 U.S. 200 (1927).

[142] *Id.* at 207.

[143] 9 Or. App. 244, 495 P. 2d 768 (1972).

[144] *Id.* at 246, 495 P. 2d at 769.

[145] *See, e.g.*, Wyatt v. Aderholt, 368 F. Supp. 1382 (M.D. Ala. 1973); *In re* Opinion of the Justices, 230 Ala. 543, 162 So. 123 (1935); Williams v. Smith, 190 Ind. 526, 131 N.E. 2 (1921); *In re* Hendrickson, 12 Wash. 2d 600, 123 P.2d 322 (1942). All the involuntary sterilization statutes in these cases were declared unconstitutional on the grounds of inadequate notice and hearing.

[146] *See, e.g.*, Skinner v. Oklahoma, 316 U.S. 535 (1942); Haynes v. Lapeer, 201 Mich. 138, 166 N.W. 938 (1918); Smith v. Board of Examiners, 85 N.J.L. 46, 88 A. 963 (1913); Osborn v. Thompson, 102 Misc. 23, 169 N.Y.S. 638, *aff'd*, 185 A.D. 902, 171 N.Y.S. 1094 (1918). All the involuntary sterilization statutes in the above cases involved imprisoned or institutionalized subjects, and were struck down on the basis of inadequate equal protection.

In January, 1976, the North Carolina Supreme Court dealt with the privacy issue when it upheld the state's decision to sterilize a minor with an IQ of less than 40. In *In re Sterilization of Moore,*[147] the Court reiterated the compelling state interest articulated in *Roe,* referring to the maternal health and potential life of the fetus, and then stated: "The interest of the unborn child is sufficient to warrant sterilization of the retarded individual . . . The people of North Carolina also have a right to prevent the procreation of children who will become a burden to the State."[148] Thus, the *Moore* court approved a compelling state interest in future generations sufficient to support involuntary sterilization to prevent conception of a future individual.[149] It also seems that the court made the audacious judgment that the as-yet unconceived child of a person like the plaintiff Moore would rather not be born at all rather than be retarded, or be neglected, or both.

The implications of *Moore* are enormous in terms of preventing genetic disease. The case appears to allow the state an inter-

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[147] 289 N.C. 95, 221 S.E.2d 307 (1976).

[148] *Id.* at 102-03, 221 S.E.2d at 312.

[149] *Id. See also* Association for Retarded Children, *et al* v. State, 420 F. Supp. 451 (M.D. N.C. 1976). The court, ruling on the constitutionality of the North Carolina sterilization statute, stated:

> We interpret Article 7 [of the law] as narrowly drawn to express only the legitimate State interest of preventing the birth of a defective child that cannot be cared for by its parent, and that so viewed, the State's interest rises to the dignity of a compelling one.

Id. at 458. *See also In re* Johnson, 45 N.C. App. 649, 263 S.E. 2d 805 (1980), where the court, ruling on the involuntary sterilization of a woman with mild mental retardation, found that the North Carolina law had "legislative dual purposes and compelling state interest . . . first, to prevent the birth of a child that cannot be cared for by its parent, and, second, to prevent the birth of a defective child." *Id.* at 653, 263 S.E.2d at 808. The court went on to find that the evidence presented at trial warranted involuntary sterilization under North Carolina law:

> The petitioner offered proof, by clear, strong and convincing evidence, that in addition to her mild mental retardation, the respondent over a period of years had exhibited emotional immaturity, the absence of a sense of responsibility, a lack of patience with children, and continuous nightly adventures with boyfriends followed by daily sleep and bedrest. Such conduct and personality traits in addition to mental retardation clearly tend to show that respondent failed to meet any acceptable standard of fitness to care for a child by providing a reasonable domestic environment.

Id. at 654, 263 S.E. 2d at 809.

est in the health of future generations so compelling as to prevent the birth of a defective child, or even a normal child born to a parent incapable of caring for it.[150] If the North Carolina Supreme Court can find a compelling state interest to prevent a *possibly* retarded from being born, as well as a compelling state interest in avoiding the burden of caring for the offspring, states may next be allowed to mandate the sterilization of an isochromosome #21 carrier, or the abortion of a fetus shown by prenatal diagnosis to be affected with Tay-Sachs disease.

If states can show a compelling interest in preventing births of defective children they still have to show that the prevention measure was the least restrictive means to achieve their goal. Thus, we can easily imagine a court striking down a law requiring mandatory screening, mandatory prenatal diagnosis, or mandatory abortion; for surely the court would ask whether a voluntary program would not be just as effective. The state would have to show that voluntary programs had been unsuccessful.

Because state-supported voluntary measures have existed for such a short time, it is difficult to conjure convincing evidence that they have not been efficacious. Even if we take an educational program (the least restrictive of actions) as our paradigm, its impact could be enormous in preventing genetic disease. And, if we look at private efforts to educate (such as those for Tay-Sachs disease), it appears that this less-restrictive means is most effective.[151] Most couples, faced with certain knowledge that their fetus is afflicted with a severely debilitating genetic disease (such as Tay-Sachs) would seriously consider termination of the pregnancy.

It seems clear that a stronger control program can be justified only if the state can show that an epidemic of serious genetic disease was at the point of draining resources of the state and imperiling the health of the gene pool. The state might argue that voluntary measures had proved inadequate, and that more restrictive measures were necessary in order to ensure the health or even survival of future generations. Absent such a scenario, states will probably remain in their role as sponsors of voluntary, less stringent control methods.

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[150] *In re* Sterilization of Moore, 289 N.C. 95, 221 S.E.2d 307 (1976).

[151] *See* Kayback & O'Brien, *Tay-Sachs: Prototype for Prevention of Genetic Disease* in MEDICAL GENETICS 253-70 (V. McKusick & R. Claiborne eds. 1973).

III. Control of Genetic Disease Through Medical Malpractice Suits

The states' relatively impotent role in controlling genetic disease does not indicate universal helplessness to prevent genetic disease. Another control mechanism is available: civil lawsuits against physicians. Control of genetic disease is largely done through dispensing information, not drugs. Potential parents are free to act on that knowledge as they wish. If they are denied vital information about their genetic "selves" and the implications for or risks to their offspring or prospective offspring, they may sue the physician for negligence.[152] These suits may be more effective in preventing genetic disease than state action, for physicians, in an effort to protect themselves from liability, will offer genetic information and reproductive alternatives to their patients. If we can assume that most people want to prevent suffering of their progeny, and would therefore act to avoid or terminate a genetically risky pregnancy, this form of genetic disease control would considerably reduce the number of infants born with severe inherited defects.

The use of lawsuits against physicians as a control measure has certain obvious advantages. It removes the state from the abortion decision, and thus removes the constitutional law constraints. And, it leaves the values of the parents intact and leaves them, armed with timely information on their offspring's potential peril, to decide its fate in privacy.[153]

A number of courts have held that the standard of care a physician owes patients may include disclosure of pertinent genetic information. In *Becker v. Schwartz*,[154] a physician failed to disclose to his patient the increased risk of Down's Syndrome in offspring of women over 35. Nor did he explain to her the availability of prenatal testing to determine whether the fetus was affected. After Mrs. Becker gave birth to a child with Down's Syndrome, she and her husband sued the physician. The court found that the physician could be liable for the expense of caring for and treating the child if the Beckers could show that the

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[152] *See, e.g.*, Curlender v. Bioscience Laboratories, 106 Cal. App. 3d 811, 165 Cal. Rptr. 477 (2d Dist. 1980); Becker v. Schwartz, 46 N.Y. 2d 401, 386 N.E. 2d 807, 413 N.Y.S.2d 895 (1978).

[153] *See* Comment, *Wrongful Life: A Misconceived Tort*, 15 U.C. Davis L. Rev. 447 (1982).

[154] 46 N.Y.2d 401, 386 N.E.2d 807, 413 N.Y.S.2d 895 (1978).

doctor had breached his duty to provide them with pertinent and timely information about the risks of Mrs. Becker's pregnancy.[155]

A number of other cases have arisen since *Becker*.[156] While there is still some controversy over who may be a party to a suit,[157] and what type of damages may be awarded,[158] the physician's duty has been largely established. Doctors must keep reasonably current on clinical developments in genetics, and pass on this information to patients who need it.

Physicians, fearing malpractice actions, now offer genetic information and alternatives to reproductive *laissez faire* without statutory prompting from the state. A damages award can bring about education, screening, counseling, and prenatal diagnosis much faster than the most comprehensive state law to prevent genetic disease, and without the constitutional law constraints.

There remains one last means of controlling genetic disease without state action. Even with genetic counseling, a pregnant woman may knowingly give birth to a defective infant. Can the

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[155] *Id.* at 407, 386 N.E.2d at 813, 413 N.Y.S.2d at 901.

[156] *See, e.g.*, Curlender v. Bioscience Laboratories, 106 Cal. App. 3d 811, 165 Cal. Rptr. 477 (2d Dist. 1980) (child and parents of child born with Tay-Sachs disease allowed to sue laboratory for negligently performing tests on parents); Howard v. Lechner, 42 N.Y.2d 109, 366 N.E.2d 64, 397 N.Y.S.2d 363 (1977) (parents allowed to recover for financial burden resulting from birth of a child with Tay-Sachs disease after the obstetrician failed to screen parents or to offer amniocentesis); Karlsons v. Guerinot, 57 A.D.2d 73, 394 N.Y.S.2d 933, (1977) (parents allowed to prove at trial that failure to do amniocentesis on 37-year-old pregnant woman, who gave birth to a Down's Syndrome child, breached a duty flowing from physician to patient which caused emotional injuries); Jacobs v. Theimer, 519 S.W.2d 846 (Tex. 1975) (parents allowed to recover expenses of caring for child born retarded after mother suffered rubella during pregnancy).

[157] Although it has been attempted many times, thus far only one child has been permitted to recover damages for injuries suffered from being born with a genetic disease. *See* note 160 *infra*. For a discussion of this issue, see Capton, *The Continuing Wrong of "Wrongful Life"* in GENETICS AND THE LAW II 81-93 (A. Milunsky & G. Annas ed. 1980); Comment, *Wrongful Life: A Misconceived Tort*, 15 U.C. DAVIS L. REV. 447 (1982). *But see* Turpin v. Sortini, 31 Cal. 3d 200, _ Cal. Rptr. _ (1982).

[158] Damages in wrongful birth suits have, with some exceptions, been limited to financial harm suffered by the parents. Courts have often disallowed damages for emotional pain and suffering on the basis of the bystander theory. *See* A. Capton, *supra* note 15; Note, *Father and Mother Know Best: Defining the Liability of Physicians for Inadequate Genetic Counseling*, 87 YALE L.J. 1488 (1978).

infant sue its mother for wrongful life?

While many wrongful life actions have been instituted against negligent physicians,[159] relatively few are taken by the child against the parent.[160] Courts traditionally have dismissed intrafamily suits,[161] except, in a few instances, when they have involved child abuse.[162] However, a pregnant woman who chooses not to abort her fetus when prenatal diagnosis reveals a genetic defect certainly cannot be classified as a child abuser in the usual sense. Those who believe that abortion is homicide must

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[159] *See, e.g.,* Park v. Chessen, 60 A.D.2d 80, 400 N.Y.S.2d 110 (1977), *modified sub. nom.* Becker v. Schwartz, 46 N.Y.2d 401, 386 N.E.2d 807, 413 N.Y.S.2d 895 (1978). In *Park* a couple gave birth to a child with polycystic kidneys (an autosomal recessive disease). The child died, and the couple consulted their obstetrician about the risk of conceiving another child with polycystic kidneys. The physician assured them there was virtually no risk. The woman again became pregnant and gave birth to a child who was affected with polycystic kidney disease. This child died also, but before death, instituted a lawsuit against the physician alleging that she had been damaged by being born. On retrial, the plaintiffs could not convince the jury that the physician had failed to warn them of the risk of conceiving another child with polycystic kidney disease; Curlender v. Bioscience Laboratories, 106 Cal. App. 3d 811, 165 Cal. Rptr. 477 (2d Dist. 1980) (parents and child born with Tay-Sachs disease allowed to sue laboratory for negligently performing tests on the couple and fetus). *See also* Gleitman v. Cosgrove, 49 N.J. 22, 227 A. 2d 689 (1967), *overruled in part,* Berman v. Allan, 80 N.J. 421, 606 A.D. 8 (1979) (parents' and child's causes of action dismissed after mother contracted rubella during pregnancy and child was subsequently born retarded). *See also* Custodio v. Bauer, 251 Cal. App. 2d 303, 59 Cal. Rptr. 463 (1st Dist. 1967); Troppi v. Scarf, 31 Mich. App. 240, 187 N.W. 2d 511 (1971); Betancourt v. Gaylor, 136 N.J. Super. 69, 344 A.2d 336 (1975); Ziemba v. Sternberg, 45 A.D.2d 230, 357 N.Y.S.2d 265 (1974). *But see* Shaheen v. Knight, 6 Lycoming Rep. 19, 11 Pa. D. & C. 2d 41 (1957).

[160] *See, e.g.,* Pinkney v. Pinkney, 198 So. 2d 52 (Fla. Dist. Ct. App. 1967); Zepeda v. Zepeda, 41 Ill. App. 2d 240, 190 N.E.2d 849 (1963). Both cases involved illegitimate children suing their fathers for the injury of having been born illegitimate. Both cases failed. *But see* Curlender v. Bioscience Laboratories, 106 Cal. App. 3d 811, 165 Cal. Rptr. 477 (2d Dist. 1980).

[161] *See, e.g.,* Hewllette v. George, 68 Miss. 703, 9 So. 885 (1891). There has been a trend toward limiting parent-child intrafamilial suits in those states where total immunity has been abolished. When issues of normal discipline and the vagaries of raising and caring for children have come before the courts, such claims usually have been rejected. *See, e.g.,* Schneider v. Coe, 405 A.2d 682 (Del. 1979); Holodock v. Spencer, 36 N.Y. 2d 35, 324 N.E. 2d 338 (1974); Goller v. White, 20 Wis. 2d 402, 122 N.W. 2d 193 (1963).

[162] *See* Note, *Parental Liability for Prenatal Injury,* 14 COL. J. L. SOC. PROB. 45, 61 (1978).

truly be anguished over the decision not to terminate such a pregnancy. To allow lawsuits against them would destroy family relationships, and would impose a value on the woman which was morally repugnant to her. In a society where individual values and mores are revered and closely guarded, legal actions by defective children against their mothers would seem to fly in the face of this reverence, and confound traditional freedom of choice. While there has undoubtedly been an injury, the remedy of suing a mother seems nearly as destructive as the injury itself.

CONCLUSION

Mandatory state action to control genetic disease encounters serious constitutional constraints. Meeting both the compelling state interest and the least restrictive means tests appears to be an insurmountable obstacle for the state. Leaving genetic control to the marketplace of lawsuits against physicians places the burden of disclosure and education on the medical profession. This is advantageous because it avoids state intervention in the decision how to or — more crucially, whether to — control genetic disease. It also effectively protects the public health by motivating physicians, through fear of lawsuits, to be aggressive in acquiring and disclosing information on genetic disease and in becoming adept in its diagnosis, prevention, and treatment. Finally, this method of private control preserves the free choice of the individual, and honors her values.