

Moving Up the Slippery Slope: Mandated Genetic Screening on Cyprus

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Many social scientists and bioethicists have argued that genetic screening is a new form of eugenics. Examination of the development of the quasi-mandated screening program for β -thalassemia in the Republic of Cyprus (1970–1984) demonstrates that there is nothing eugenic about modern genetic screening practices. The Cypriot screening program involves mandated premarital carrier screening, voluntary prenatal diagnosis (originally through fetoscopy, now through CVS), and voluntary termination of afflicted pregnancies—all at public expense. In the Republic of Cyprus, the mandating agency for genetic screening is the established church, so this examination also demonstrates that religious authorities with profound objections to abortion can balance that moral precept against others, such as the imperative to reduce suffering that sometimes conflict with it.

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INTRODUCTION

For the last two decades, it has become fashionable, in some academic and political circles, to speak of the social implications of genetic medicine as “the new eugenics,” implying that the modern regimens of genetic screening (and, potentially, the future regimens of genetic enhancement) are little different from—and certainly no better than—the social

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¹Some opponents of prenatal diagnosis claim that their use of the term new eugenics is not meant to signify that this form of genetic screening is akin to Nazi eugenics, but only that women who choose to terminate pregnancies with afflicted fetuses have internalized standards of normality which foreclose the possibility that a disability is compatible with a good quality of life. This claim, in my view, is both wrongheaded and disingenuous. I do not have the space in this paper to explain why, except to say that eugenics is about state control of reproduction, not about internalized standards of normality. Opponents of prenatal diagnosis who refer to it as the new eugenics are deliberately using that language in order to conflate the one with the other. [Cowan, 2008, esp. ch. 7].

[e.g., Duster, 1990; Holtzman, 1998; Sandel, 2008]. The original eugenicists wanted to improve the genetic quality of the race (by which term some of them meant “the human race” and others meant “the racial group to which I belong”) by reproductive means, either by encouraging the reproduction of the people they thought of as “fit” (this was positive eugenics) or by preventing the reproduction of people whom they deemed “unfit,” (this was negative eugenics). Negative eugenics was to be accomplished either by state-mandated sterilization or by forced residential segregation by sex, in state run institutions or, in the extreme case, by state ordered murder. Nazi Germany was, of

course, precisely that extreme case, and it is the memory of what the Nazis once did in the name of eugenics that leads some commentators to fear that modern regimens of genetic testing will lead us back to the moral abyss that the Nazis once inhabited.

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The clinicians, researchers, patients, and patient advocates who created the modern regimens of genetic screening were, and still are, to use the phrase popularized by the anthropologist Rayna Rapp, “moral pioneers” [Rapp, 1987]. Indeed, these pioneers have led us not only out of that abyss but also so far up that slippery slope that genetic screening, as it is practiced today, is almost the complete opposite of earlier eugenic practice. In that pioneering effort, medical professionals, patients, and patient advocates have been assisted not just by people of faith but also by members of the clergy. There is no better illustration of these points than the history of the quasi-mandated genetic screening program for β -thalassemia in the Republic of Cyprus.

EUGENICS

The eugenics movement began in the latter part of the 19th century in England [Cowan, 1985; Kevles, 1985]. The founder of the movement, Sir Francis Galton believed that once scientists understood the principles of Darwinian evolution, they could apply those principles either to improve the whole human race, or to have one race improve so much that it would drive the others to extinction.

No governmental body ever made positive eugenics, encouraging the better people to breed more, official policy. On the other hand, negative eugenics, the effort to prevent those who were deemed genetically deficient from reproducing so as not to perpetuate their

traits in subsequent generations, was mandated, in the form of compulsory, involuntary, sterilization, in two countries: the United States and Nazi Germany. In the United States, for almost half a century, beginning in 1907, a very large number of states mandated sterilization for persons in state care (in publicly funded residential facilities for the mentally retarded or in jails and prisons) who were deemed likely to pass their negative traits (principally what was then called feeble-mindedness) on to their offspring. Between 60,000 and 150,000 Americans were sterilized without their consent under these eugenic laws [Reilly, 1991; Bruinius, 2006]. (In Scandinavia, which began to legalize eugenic sterilization and abortion in the 1930s, consent was always required, either from the individual or from a family member; this is why Scandinavian eugenics is not regarded as being at the bottom of the moral slope [Paul, 1995; Broberg and Roll-Hansen, 1996].)

In Germany, after the advent of National Socialism in 1933, compulsory eugenic sterilization was made legal not just for the institutionalized population, but for anyone suffering from any of what were defined as dys-eugenic conditions, ranging from feeble-mindedness, to epilepsy, alcoholism, and homosexuality [Proctor, 1988]. Ministers, teachers, and physicians were required to report to the court families or individuals in which any of these conditions were evident. The court could then remand individuals for sterilization. In addition, a court could remand individuals (both children and adults) to sex-segregated institutions, so those individuals could be prevented from breeding. Toward the end of the 1930s, many of the residents of these institutions were “euthanized,” not by law, but by executive edict.

The moral pit which lies at the bottom of the slippery slope is one in which persons who are thought to be genetically defective can be forcibly prevented from reproducing—or can be killed—by order of their own government. In that pit, professionals—physicians, nurses, teachers, ministers—can

all be required to participate in the effort, even if they find it reprehensible: in Nazi Germany, stiff fines were leveled against those professionals who failed to report afflicted patients or students or congenants to the eugenic court system.

MODERN GENETIC SCREENING

The modern regimens of genetic screening began to develop in the 1950s. Sex chromatin (Barr body) analysis of fetal cells floating in amniotic fluid was first reported (by four different research groups) in 1955; the first diagnosis of sex done prenatally, through amniocentesis was announced in 1960, the same year in which newborn screening for PKU by bacterial inhibition began. The earliest published report of prenatal diagnosis for a chromosomal abnormality appeared early in 1968, by 1971 three separate clinical trials of amniocentesis for trisomy 21 were underway and the technological systems through which carrier screening for sickle cell anemia and for Tay–Sachs disease could be accomplished had been at least partially automated [Cowan, 1993].

Both the social goals and the social character of genetic testing were, therefore, established before the early 1980s, which is when genomic analysis became clinically useful; genomic analysis may have expanded both the range and the accuracy of prenatal diagnosis, carrier testing, and newborn screening, but it has done nothing to alter the social patterns that were established in the 1960s and 1970s—and these social patterns were fundamentally non-eugenic.

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to prevent people whom they deemed genetically unfit from reproducing; medical geneticists wanted precisely the opposite, to enable such people to have healthy children. Eugenecists wanted governments to sanction and pay for these programs and so, sometimes, did medical geneticists, but there was a profoundly important difference between what the two groups of geneticists hoped to mandate; eugenecists wanted to require both the testing and the reproductive limitation, while medical geneticists wanted to insure only the testing, leaving reproductive decisions to individuals. Several modern medical

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geneticists in positions of public health authority have argued that genetic screening should either be mandated or made easily accessible so as to lower the health burden for families and communities, but after the end of World War II none have argued (at least not publicly) that that goal justified mandating abortion of afflicted fetuses or sterilization of carrier adults.

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β -THALASSEMIA

β -Thalassemia is, like sickle cell anemia, one of the single gene recessive hemoglobinopathies; heterozygotes are reasonably healthy people but homozygotes are very, very ill—from infancy [Weatherall and Clegg, 1979]. Like sickle cell anemia, β -thalassemia carrier rates are high in populations that live, or once lived, in places in which malaria was once, or still is, endemic. The disease was first identified, in the 1920s, in the United States, amongst the children of Greek and Italian immigrants [Cooley and Lee, 1925]; its prevalence in the United States is currently growing, as the result of immigration from southeast Asia [Lorey and Cunningham, 1998]. Cyprus, where two mandated screening program developed, has one of the highest carrier rates in the world: 1 in 7.

β -Thalassemia is, of course, an existentially dreadful disease: dreadful for patients, their families, and also their physicians; doubly dreadful because

both its symptoms and its treatment are physically and emotionally painful, or were, until very recently. Babies who are born with β -thalassemia do not make adult hemoglobin. In their first few months of life, they appear to be completely normal, but around their 6 months they become listless and their rate of growth and development slows down; this is because fetal hemoglobin is not being replaced by adult hemoglobin. Left untreated a child with β -thalassemia will develop characteristic anatomic anomalies—and will decline slowly and fatally, sometime between the ages of four and six.

By the mid-1930s, pediatricians had discovered that if a thalassemic child was given regular and concentrated blood transfusions early enough in its life, the anatomic anomalies would not be as severe and the child could be kept alive somewhat longer. Such a treatment could not, however, be given to most afflicted children until there were blood banks and mass produced hollow needles small enough to be inserted in a child's tiny veins. In 1942, Allan Fawdry, the first physician to attempt transfusion therapy on Cyprus, expressed the kind of existential quandary that the disease used to create, both for parents and for physicians:

When transfusion is repeated many times, severe and even fatal febrile reactions may occur; the technical difficulty of infusing blood into the minute veins of small children becomes well-nigh insuperable; the finding of compatible donors becomes almost as exhausting as the performance of the transfusion; *and one faces the metaphysical problem of whether for a child a continued life of semi-invalidism frequently punctuated by the unpleasant experience of transfusion is better than no life at all* [Fawdry, 1942, italics added].

After World War II, transfusion was offered more routinely, at least in Britain and the United States, in major urban hospitals—but the existential problem did not disappear; pediatricians who were offering regular transfusion with double concentrations of red blood cells were saddened to discover that their

patients were, nonetheless, not reaching adulthood. Their patients all died, sometime in adolescence, often from the failure of one or more major organs, a result of the accumulation of elemental iron in their tissues.

In 1960, an iron-chelating drug, deferoxamine, came on the market, a chemical which combined with elemental iron to make it water soluble, and therefore excretable; within a few years physicians had demonstrated that this drug (the trade name was Desferal), if given by infusion, successfully cleared excess iron from the tissues of children with β -thalassemia, thereby raising the possibility of an average, or nearly average, lifespan [Modell and Beck, 1974]. By 1990, many of the children who had had access to Desferal and transfusion treatment since infancy, had, in fact, reached adulthood.

Unfortunately, there is a world of pain and suffering encompassed in the four words “if given by infusion”. Infusion takes many hours and, for most thalassemics, it has to be done daily. A small, almost pocket sized pump was developed for this purpose; thalassemic babies are often put to sleep with the pump in operation; adolescents and adults usually do their infusions during quiet times of the day. To be most effective, chelation should start when transfusions start, usually around 6 months of age, which means that parents must inflict daily pain upon their children—until the children are old enough and willing to do it themselves. On top of all this, Desferal was (and still is) very expensive, which means that parents often have had to experience the pain of worrying about whether they could afford to keep their children alive. All that chelation-related pain and suffering, experienced not only by patients but also by parents and by medical professionals, may no longer be necessary, as an effective orally administered iron chelator has recently come on the market [Barton, 2007]. Painful, daily, life-long administration of an expensive life saving medication was, however, the essential context in which several groups of Cypriots decided to create a mandated genetic screening program.

CYPRUS

Cyprus as the second largest island in the Mediterranean; malaria had been endemic there for several millennia, until it was eradicated in the 1950s. In square miles, Cyprus is geographically quite small (about the same size as Long Island, New York); since the mid 1970s, it has been split into two independent national units, which do not recognize each other as independent national units. The southern part, the Republic of Cyprus, is represented in the United Nations and has general diplomatic recognition. Since 1975, all the residents of the Republic of Cyprus have been of Greek ancestry—and the vast majority of them are Cypriot Orthodox Christians. Like all the other Orthodox churches, the Cypriot Orthodox Church is self-governing; it is only loosely coordinated with the other, geographically defined, Orthodox churches, but like them, and like the Roman Catholic Church, it is doctrinally adamant in its opposition to abortion.

The Cypriot Orthodox Church is the established church of the Republic of Cyprus—which is one of the many reasons why the northern third of the island is today separately governed by the Turkish Republic of North Cyprus, a governmental entity which is not recognized by any other government, except the government of Turkey. Citizens of the Turkish Republic of North Cyprus speak Turkish. At the time that the Turkish Republic was created, in the late 1970s, its founders were, like the political elite of Turkey itself, secular Muslims.

Both governments on Cyprus are parliamentary democracies with elected chief executives. Each of them has a mixed medical economy; a national health care system exists in each, but each is paralleled by a private system, accessed principally by the more affluent citizens. Another thing that the two Cypruses have in common is the carrier rate for the several mutations that can cause β -thalassemia; one in seven is the rate for all Cypriots, whether of Greek or Turkish heritage.

Each of the two parts of Cyprus mandates premarital carrier screening for β -thalassemia—but the mandating authority differs. In Turkish Cyprus, the mandating authority is the government; indeed, the law mandating screening was one of the first laws passed by the Turkish Cypriot parliament when it came into existence in 1979 [Cowan, 2008, 208–210]. In Greek Cyprus, the mandating authority is the Cypriot Orthodox Church. And thereby hangs a very complicated story.

MANDATING GENETIC SCREENING FOR β -THALASSEMIA IN THE REPUBLIC OF CYPRUS

When Cyprus became independent of Britain, in 1960, it inherited a fairly good medical infrastructure, especially in its capital city, Nicosia, as well as a corps of British trained physicians, nurses, pharmacists, and technicians. At that time, like many newly independent colonies of Britain, Cyprus became a member of the British Commonwealth. Commonwealth membership had three important health care consequences for Cypriots, no matter whether they were of Greek or Turkish heritage: first, under grants from the British Council, Cypriot medical professionals could go to Britain for advanced training; second, larger numbers of young people could go to Britain for basic healthcare training, and third, patients who could afford the trip could go to Britain for treatment, where they would receive it at virtually no cost.

By the end of the 1940s, medically educated Cypriots had been aware that β -thalassemia was a substantial public health problem on the island. Twenty years later, by the end of the 1960s, Cypriot medical professionals were very well acquainted with the advances that had been made in thalassemia treatment (both in transfusion and in chelation) in Britain and in the United States. Not long after independence,

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a special ward had been set aside in Nicosia General Hospital for transfusing thalassemic children and by the early 1970s the parents who had met each other on the ward had joined with the physicians to start what would today be called a patient advocacy group: The Cyprus Antianaemic Society (now the Thalassemia International Federation). A civil war broke out between the Greek and Turkish populations during the winter of 1963–1964. The area around the hospital was the site of intense fighting, and when the shooting stopped, the hospital had remained in the possession of the Greek Cypriots. As a result, all the Turkish Cypriot medical staff resigned from service and began treating Turkish Cypriot patients in separate facilities. Much of the remainder of the story on which this paper focuses therefore concerns only the Greek community.

The goal of the Antianaemic Society was "...to create, in Cyprus, the essential conditions to attain the highest possible percentage of survival" [Cyprus Antianaemic Society, 1974]. The Society intended to pressure the government into creating a blood bank on the island; it also wanted the government to cover the cost of Desferal therapy, as the rich parents who were importing the drug on their own soon realized that their less affluent peers were having trouble get-

ting access to it. Both efforts were successful.

In the first decade of independence, between 60 and 80 babies with thalassemia were being born every year, and the physicians who were treating these babies began to worry about how their economically struggling government was going to be able to afford to treat all the adults those babies were going to become if transfusion and Desferal did their therapeutic work successfully. After requesting funds from the World Health Organization, they invited George Stamatoyannopoulos, a medical geneticist at the University of Washington, to visit the island in order to make precise estimates of both the incidence and carrier rate for β-thalassemia, using improved biochemical tests that he had developed.

In his report to the Ministry of Health (and in a subsequent publication), Stamatoyannopoulos concluded that if the Cypriots offered the best available treatment regimens to the current population of patients, each patient would be likely to live into middle age. A not insignificant consequence would be that medical costs on the island (which, at the time, had a completely nationalized health care system) would escalate—and would escalate even further if several dozen new patients were born every year, each with a fairly normal life expectancy [Ashiotis et al., 1973]. Absent a prevention program, Stamatoyannopoulos estimated that the prevalence of β-thalassemia would go from 1:1000 to 1:138 in the next 50 years, creating an increase of 300–400% in the demand for blood and of 600–700% in the cost of treatment. Cyprus would soon find, he argued, that the needs of its thalassemic patients would completely engulf not just the available blood supplies but also the entire budget of the Ministry of Health [Stamatoyannopoulos, 1972].

Carrier screening coupled with reproductive counseling was a possible solution, since carriers could be identified by a relatively simple blood test. The physicians already knew that many obligate heterozygotes resisted having their non-thalassemic children tested for

fear of damaging those children's marriage prospects so they searched for other populations of not yet married young people to screen: they tried getting high school biology teachers to send their students for testing, with some success—and, a few years later, they began testing army recruits [Angastiniotis, 1999; Hadjiminis, 1999].

By the late 1970s, prenatal diagnosis of blood had become possible, through the development of fetoscopy [Woo, 2008]. The Greek pediatricians who pioneered carrier testing thus decided to change strategies. They already knew, from their experience with the parents of children with thalassemia, that these couples were reluctant to use birth control, but that the women, in pregnancies subsequent to the birth of an afflicted baby, would often, and often without the knowledge of their spouses, seek abortions. To put the matter another way, the pediatricians had good reason to believe two things: first, that when thalassemia was diagnosed in a pregnancy, Cypriot women would not hesitate to terminate it; and, second, and possibly even more important, over time, prenatal diagnosis would actually reduce the number of abortions that carrier women would seek, since there was only a one-in-four chance that any particular pregnancy would be affected.

Consequently, the pediatricians began to focus on informing their obstetric colleagues of the need to do carrier testing in prenatal care and to recommend follow-up to the thalassemia specialists for counseling. As a result of all these strategies, the number of babies born with thalassemia began to fall, slowly at first and then more rapidly; in 1982, 10 years after Stamatoyannopoulos had issued his warning, only eight thalassemic babies were born in Greek Cyprus, 90% fewer than what demographers would have predicted [Angastiniotis et al., 1988].

Nonetheless, several of the thalassemia specialists remained unsatisfied because the number of babies born with the disease each year had not yet fallen to zero, which is where they wanted it to be. There were several reasons for their dissatisfaction. The first, as Minas Hadjiminis,

then the Director of the Thalassemia Center in (Greek) Nicosia explained in an interview,

The suffering, the suffering: you can't imagine it. We had so many disasters. I saw one woman commit suicide. I saw kids left to die after the diagnosis. . . . "I wanted 100 percent; 100 percent was important to me. I don't want people miserable" [Hadjiminas, 1999; italics convey conversational emphasis].

Another, focused more on the social medicine approach to individual suffering, was expressed subsequently by Michael Angastiniotis, then the Assistant Director of the Center.

I still believe what I was taught as a medical student in England in the 1960s; preventive medicine is the best medicine to practice, because it is best for the whole society. Where β -thalassemia is concerned, screening is preventive medicine—and what it prevents is suffering [Angastiniotis, 1999].

In addition, the Cypriot thalassemia specialists had come to realize that the public education effort needed to keep up their screening program was diverting both expert time and lots of money from the treatment effort, which was becoming more complicated as thalassaemic people began living longer. They also knew that in Turkish Cyprus premarital screening for heterozygosity had already been mandated by its new government; the requirement that no couple could receive a license to marry in the Turkish Republic of North Cyprus unless both parties to the marriage presented a certificate saying that each had been screened for carrier status and had subsequently been counseled by a thalassemia specialist had been one of the first pieces of legislation passed (unanimously) by the Turkish Cypriot parliament, shortly after it came into existence [Cowan, 2008, 208–210].

Sometime in the early 1980s, the Antianaemic Society began to lobby the government of the Republic of Cyprus to mandate screening, but they were regularly rebuffed; no legislator would

vote for it, they were told, fearing the wrath of the established church. As a consequence, the physicians and parents requested a meeting with Archbishop Chrysostomos (then the head of Church) and the bishops who consult with him on church policy.

They presented three arguments in favor of mandating a premarital certificate. First, as shepherd to his flock the Archbishop ought to act so as to reduce suffering, which a premarital screening program would unquestionably do, since it would reduce, to zero with any luck, the number of babies born with β -thalassemia. Second, as an opponent of abortion, he needed to understand that premarital screening would, also unquestionably, lower the abortion rate amongst Greek Cypriots, since most women in heterozygote marriages who were not using prenatal diagnosis were terminating all their pregnancies subsequent to the birth of a thalassaemic child. Finally, the patient advocates argued, as the head of a community that was diminishing in size (because of emigration and a lowering birth rate) the Archbishop ought to do all he could to encourage men and women in heterozygote marriages (roughly 1 in 49 Cypriot couples were both carriers) to have as many children as possible.

In 1983, the Archbishop announced that, henceforth, priests of the Cypriot Orthodox Church could request a certificate from each member of a couple wanting to be married in the Church. The certificate, which was soon formalized, was to be issued by the Thalassemia Center in Nicosia; it attested (and still does) to the fact that an individual had been both screened and counseled at the Center. In terms of

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both religious and civil law, presentation of the certificate is only quasi-mandated; priests do not have to ask for it and couples do not have to present it. In terms of social reality, however, virtually all priests do ask and virtually all couples do get screened. At the dedication of the Thalassemia Center's new building, in 1981, Chrysostomos had delivered a long speech about the evils of abortion. In 1986, 3 years after he made his announcement approving premarital screening, the physicians' goal of zero thalassemia births was finally achieved.

ACHIEVING MORAL AND POLITICAL CONSENSUS ABOUT GENETIC SCREENING

The Republic of Cyprus is a democracy; it has an elected executive and an elected legislature, several political parties and a more or less free press. Its premarital screening program is not conducted in secret. Virtually all couples married in the Republic since 1984 have been screened and counseled at the Thalassemia Center, which is adjacent to one of Nicosia's two large hospitals, The Archbishop Makarios Hospital for Women and Children. In a small population, with a carrier rate of 1 in 7, just about every citizen knows someone who is in a heterozygote marriage and because the Thalassemia International Federation continues active fundraising efforts, just about everyone on the island either knows someone with thalassemia or knows a lot about its causes and its treatment.

Various agencies of the Cypriot government have acted in support of

the screening program, from its initial inception under physician auspices through its re-creation as a quasi-mandated collaboration of the same physicians and the priests of the Orthodox Church. In the early days, the Ministry of Health paid the salaries of the technicians who processed the screening blood samples, just as it paid for the equipment and the supplies that were required—and it still does. The Ministry also paid the travel expenses of women who journeyed off the island for abortions in the early years, just as it paid for the trips some pregnant women made to London for prenatal diagnosis, either through fetoscopy or, later, through chorionic villus sampling. In 1986, the Cypriot legislature, emboldened by what the Church had decided to do 2 years earlier, finally made abortion for fetal indications legal in the Republic, which means that today, women who cannot afford to go to a private clinic for an abortion, can have it done (if the results of CVS are positive for thalassemia), at public expense, in the hospital that bears the name of the previous Archbishop [United Nations Population Policy Databank, 2008].

Despite the Orthodox Church's opposition to abortion, despite active governmental support for this type of genetic screening, and despite what educated Cypriots must know about the history of eugenics under the Nazis, for the last quarter century there has been virtually no opposition (except for those gynecologists who will not perform abortions) to premarital screening, prenatal diagnosis, and follow-up termination of afflicted pregnancies. This somewhat astonishing political consensus was achieved by the creation of what can only be called a moral consensus, a consensus promoted by the moral values of four different sets of social actors: the physicians who cared for patients with thalassemia, the parents of these patients, the bureaucrats who supported their efforts, and the church to which most of them belong.

The moral imperative for physicians was to reduce suffering by preventing the birth of persons with a severely debilitating disease. The moral imper-

ative for governmental officials was to provide the greatest good for the greatest number within the constraint of the available resources; calculations undertaken in the 1980s indicated that the each thalassemia patient cost the Cypriot government £84,210 a year (there were, then, roughly 600 patients in Greek Cyprus) while the entire prevention program cost £130,696 to run [Angastiniotis et al., 1988]. Parents acting as patient advocates through the Antianæmic Society, had two, somewhat different perspectives. They supported screening because they feared that if the population of patients continued to grow larger, something on which their children's well-being depended—blood, Desferal, psychologist's services, interferon (many had contracted hepatitis C)—was going to have to be rationed; they acted out of what might be called the parental imperative, to protect the lives of their children. In addition, they advocated for the screening program altruistically, hoping that “no one else would have to suffer the way my child and I have suffered:” doing for others what you would have done for yourself. The Cypriot Orthodox Church also acted parentally, or, to use a more appropriate synonym, patriarchally; as shepherds to their flock the church council apparently decided that, in this case, the imperative to protect human life could best be followed by reducing abortions, encouraging childbearing, and reducing suffering amongst the faithful.

CONCLUSION: MOVING UP THE SLIPPERY SLOPE

The people who designed the quasi-mandated genetic screening programs in the Republic of Cyprus succeeded in avoiding all that what was evil in earlier eugenic practices; indeed, the Cypriot version of thalassemia screening is so far removed from eugenics that it should not even be called by the same name.

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Eugenicists wanted to prevent people whom they deemed genetically unfit from reproducing; the Cypriot program is designed to do just the opposite, that is, it is designed to encourage carriers of disease-causing genes to have as many children as they want. Eugenicists, furthermore, wanted governments to sanction, pay for and require both genetic testing (such as it was in those days), and reproductive limitation; the Cypriot program requires only the testing, leaving the reproductive decisions entirely to parents. Eugenics programs were designed in the hope of improving the quality of an entire population; the Cypriot program was designed to lessen individual suffering.

The evidence that these precepts were consciously on the minds of those who designed and supported the premarital certificate abounds. That the program was designed to be prenatal, rather than anti-natal for heterozygotes is made clear by the fact that obligate heterozygotes began increasing their fertility after prenatal diagnosis became available; indeed, some heterozygote women were willing to risk, when pregnant, not just a trip to London, but also subjecting themselves to a potentially dangerous experimental procedure (fetoscopy) in order to insure a non-thalassemic child [Modell et al., 1980]. That the program avoids trying to influence parental decisions is made clear by the facts, first, that both prenatal diagnosis and consequent termination of afflicted pregnancies are paid for by the Ministry of Health and, second, that couples who decide to carry an afflicted

fetus to term (some couples, including a homozygote couple, have indeed made this decision, although not very many) are assured that all their thalassaemic child's medical costs will be covered, at public expense, for life. That the population's genetic health was less (far less) important than the reduction of individual pain and suffering to those who initiated screening is made clear by the fact that predictions about the future frequency of thalassaemia mutations were never part of the public (or even, as far as close observers can tell, the private) conversation about screening. (Such predications would have been impossible to make sensibly, in any event, since it would have been impossible to know how both the eradication of malaria, the increasing exogamy of the population and the initial decreases and subsequent increases in the fertility of known heterozygotes would have influenced the frequency of carriers.)

The quasi-mandated genetic screening program in the Republic of Cyprus demonstrates that it is possible to screen for genetic disease and to prevent the birth of afflicted babies, without being eugenic; that it is possible, to put the matter another way, to practice medical genetics without even broaching the slippery slope that ends in eugenics.

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To make this point clear, just think what might have been the fate both of

thalassaemia heterozygotes and their afflicted offspring in Nazi Germany. The adults could well have been remanded for sterilization by a eugenic court; the children could well have been sent to residential facilities either for withholding of treatment or for extermination.

The fact that the mandating agency, in this case, is an established church profoundly opposed to the taking of fetal life, demonstrates that there are people of deep faith who recognize that ethical precepts often provide conflicting directives and that it is possible to act pragmatically as well as ethically, even when such a conflict arises. If modern

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regimens of genetic screening had not been anti-eugenic, that balancing act would not have been theologically acceptable to the leaders of the Cypriot Orthodox Church. These clergymen thus joined clinicians, researcher, patient advocates and government officials as moral pioneers, as they all moved up and away from the ethical slippery slope that has eugenics at the bottom.

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