Genetic Advances Outpace Efforts To Craft a New Ethical Paradigm

Jarring contradictions and disparities are rapidly emerging in the profoundly promising — and hazardous — field of genetic diagnosis and treatment.

A broadly representative conference here last month explored the ethical implications of this new genetics. The problems brought to light reflect the technology’s rapidly improving ability to predict, and thereby trigger efforts to prevent illness, suffering, and death from a growing number of both rare and common inherited diseases.

But in medicine, diagnosis usually precedes therapy by months, years, or even centuries. The genetic tests also can and do reveal unhappy fates at unwanted times — much as the AIDS virus tests do.

The question, then, is how should this information, which could affect almost anyone, be dealt with.

Future Is Forecast

The genetic tests yield “powerful sets of information that can shape people’s lives,” warned geneticist Phillip Reilly, M.D., J.D., who directs the Eunice Kennedy Shriver Center for mental retardation research in nearby Waltham. The most challenging facet of these tests, Reilly declared, is their ability “to predict future illness in healthy people.”

These predictions can be made in childhood, in utero in time for the mother to choose an abortion, and, recently, even prior to pregnancy — which may be a less distressing option (See adjacent story). They also may show that healthy young adults are fated to die in middle age of cancer.

The conference that examined these paradoxes was convened May 5, by Public Responsibility in Medicine and Research (PRIM&R), a 20-year-old Boston organization that scouts the boundaries between research, clinical care, and daily life. The 300 registrants included academic physicians, geneticists and genetics counselors, ethicists, lawyers, biotech leaders and reps, and administrators of the Human Genome Project (HGP) and other government agencies. Genetic counselors were particularly well represented.

Question Is Posed

The program asked, provocatively: Does research on genes require a new ethical paradigm?

The answer from one panel of experts was, more or less, continued on page 4

Jews and Cajuns Finding Benefit In Tay-Sachs Tests

The high risk of Tay-Sachs disease, a painful, disabling, and eventually lethal genetic disorder, has prompted highly conservative orthodox Jews to create a trend-setting method to forestall the birth of affected infants. Their system is not based on abortion — which they oppose.

More dramatically, a second — highly experimental — new method allows doctors to examine at risk couples’ pre-embryos, prior to pregnancy, to guarantee that the baby will not be affected.

Tay-Sachs is much more common among orthodox Jews, and among Cajuns, in Louisiana, than in other ethnic groups, because of inbreeding. Among the Jews, about one in each 3,000 births has been affected. The infants are in great distress and require constant care until they die.

Parents who have had one Tay-Sachs baby don’t want continued on page 6
Follow Up..." winners & sinners: we complain a lot about colleagues' work—which is what critics are supposed to do. we also pick some winners:

the news photo of the vulture preparing to eat a dying african girl—which we described in our report on population pressures last may—has won new york times photographer kevin carter the pulitzer prize for feature photography. this january, we published a précis of chicago tribune science writer ronald kotulak's series on genes, neurotransmitters, and violence—a series that won kotulak the pulitzer for explanatory journalism.

we are far less happy with the work of kotulak's colleague at the trib, john crewdson, who reportedly sought "a rare second pulitzer prize" several years ago with his allegations against aids researcher robert gallo, m.d. (gq, april, '91, p. 151). these charges have now been discounted or dismissed.

recently, crewdson stirred women's fears with reports on "fraud" in breast cancer studies at the university of pittsburgh; we think he vastly—and unfairly—exaggerated the problems (probe, april, may).

crewdson, who is not a science writer, mistrusts scientists.

the price of tea...: our toughest editor ex post facto, tom watkins of cnn, points out that we did not give the price of laci le beau ® super dieter's tea ® last month when we described its laxative properties; it contains the cathartic senna. a box of 15 bags of the tea costs $3.99 at the health food store on our corner.

watkins also points out that we meant to say that, generally speaking, the health food industry flouts, not flouts food and drug administration regulations. to be precise: some companies flout the rules in flaunting their wares.

speaking of senna: the suffering of england's "mad" king george iii (1738-1820) has captured the avocational attention of psychiatrist shale brownstein, m.d., of columbia university, in new york. the king's craziness, brownstein tells us, is usually ascribed to the royal malady porphyria, a blood disorder that ran in his family.

reviewing the records, brownstein demurs:

he says george's primary diagnosis was what then was called a "nervous disorder"—quite probably manic depressive psychosis, in today's terms. then, as now, brownstein says, people's attitude was:

"don't tell me our king is crazy!"

compounding george's discomfort were frequent dosings with senna—which is a powerful cathartic—as well as quinine, mercury and antimony. the aim: to purge his illness.

senna causes water-retention and swelling of the extremities. while the royal dosage is unknown, brownstein says, "they gave him so much senna that he couldn't get into his shoes!"

porphyria, brownstein adds, doesn't produce the extraordinary mania that george suffered. he cites this diary entry by one of the queen's ladies in waiting, to illustrate an extreme, early eruption of the king's manic illness:

"i had a sort of conference with his majesty, or rather i was the object to whom he spoke, with a manner so uncommon, that a high fever alone could account for it; a rapidity, a hoarseness of voice, a volatility, an earnestness—a vehemence, rather—it startled me inexpressibly. yet with a graciousness exceeding even all i ever met with beforehand—it was almost kindness!"

'encyclopedia of violence' dissects our social woes
it is much easier to commit violence, or react to it, than it is to think clearly about it. we recognize violence, but, particularly in its all-too-common expressions, we don't quite know what to make of it.

medical sociologist margaret dicanio, ph.d., of marblehead, mass., has now provided a very readable, and hence useful thinking aid: she has written an encyclopedia of violence on the origins, consequences, and attitudes toward violence (new york: facts on file, 1993, $45).

the effort to systematize this subject is a start toward understanding it. more important, by breaking violence down into short entries and essays—with headings such as anger, manslaughter, and self-mutilation—dicanio provides handles that help readers focus in on the topics. what to do about violence?

dicanio thinks the first priority is to study it more systematically. for this reason, she said last month by phone, she favors the creation of a violence institute, in washington, comparable to one of the national institutes of health.

this would be "the first effort to take violence out of the criminal justice sector, and treat it as a public health problem—which is what it is," dicanio said.

order from facts on file: 1-800-322-8755.

probe editor and publisher david r. zimmerman

editor is afield; july issue will be late
we have the extraordinary good fortune to have been awarded a science writing fellowship by the marine biological laboratory, in woods hole, mass. we'll be at this renowned research institution in june.

for this reason, our july deadlines will be late, and we will mail the july probe later than usual. — d.r.z.
Some readers say they were astonished by our reporting that the breast cancer fraud story — which has terrified many women and shaken public trust in science and medicine — was wildly exaggerated (PROBE, April). It also was basically untrue.

We pointed out that the falsifications did not alter the results. The reporters whose stories we criticized, John Crewdson of the Chicago Tribune and Lawrence Altman of the New York Times, did report statements to this effect, but quickly dismissed them.

The statements came from the study organizers, the National Surgical Adjuvant Breast Project (NSABP), in Pittsburgh, the National Cancer Institute (NCI), and the Public Health Service's Office of Research Integrity (ORI), near Washington, D.C.

Altman also quoted an expert who worried that subtracting the suspect cases would weaken the statistical power of the study, which found that lumpectomy is equal to radical mastectomy in saving the lives of women with early breast cancer.

A reassuring statistical reanalysis of the data — the umpteenth — has now been available for over a month. But we don’t remember Altman writing a science story about it in the Times, which, as the paper-of-record’s man on the case, one might expect him to do. We don’t read the Trib regularly, and so cannot say if Crewdson has shared the specific and reassuring data with his paper’s readers.

Below is the news story we think the Times, Trib and other media should have presented, with urgency and clarity — but, as far as we know, have not:

**Lumpectomy Results Remain Solid**

BETHESDA, April 15 — The Public Health Service announced here today that a new reanalysis of falsified data in a key study has confirmed the effectiveness of breast-sparing lumpectomy in women with early breast cancer. The results remain "unchanged," the National Cancer Institute's acting deputy director, Edward J. Sondick, declared in a written statement.

Sondick said the study had been re-analyzed, outside of the government, by a biostatistical consulting firm, EMMES Corp., of nearby Potomac, Md. The firm reexamined the results of the lumpectomy study, and several related clinical trials by the National Surgical Adjuvant Breast Project (NSABP) with and without the cases contributed by surgeon Roger Poisson, M.D., of St. Luc's hospital, in Montreal. The EMMES statisticians used the NSABP data file in their reanalysis, the company said in its report. In all key parameters, EMMES said:

"[R]esults from St. Luc's are within 3 percentage points of the remaining centers combined, and no difference is more extreme than would be expected by chance." The "relative treatment results are similar with and without St. Luc entrants."

The original study, in fact, turns out to have been specifically designed to negate the kind of falsifications that occurred — most of them date changes to allow ineligible women into the study. This strategy worked, protecting the study's validity, the EMMES group said.

Here are some of the key findings: Among 1,855 eligible women who accepted the randomly assigned therapy, 37.4% were alive on September 30, last year. Of these, 328 were treated at St. Luc's, and 37.5% of them survived. Among the 1,527 women at all other participating hospitals, 37.3% survived.

The St. Luc's results thus were one one-tenth of a percentage point different from the total results. Discarding the St. Luc's data changed the over all findings by only two-tenths of a percentage point.

"Importantly," the EMMES analysts say, "despite the decrease in sample size [from 1855 to 1527 women] the upper endpoint of the confidence interval" is increased by only .01 [from 1.26 to 1.27]. This means that subtracting St. Luc’s does not meaningfully increase the possibility of lumpectomy being worse than mastectomy, EMMES president, Donald M. Stabilein, Ph.D., explained by phone. Stabilein, a biostatistician, wrote the report. He said that in other comparisons removal of the St. Luc's data actually decreased the possibility that lumpectomy is worse than mastectomy.

"Exclusion of the data from St. Luc has no substantive effect on the main study findings," Stabilein and his EMMES associates conclude. "It should be recognized," their report adds, "that the randomized study design prevents fraudulent pre-entry data from biasing the treatment comparison."

This means that the kind of falsifications Poisson made could not change the comparative results between lumpectomy and mastectomy. As Stabilein explains it, the study was specifically designed to nullify falsifications like Poisson's that were made before women were randomly divided into one treatment group or another.

**Much Credit Is Due**

"Bernard Fisher [who directed the lumpectomy study] conducted a randomized study that was difficult to do, because it was a surgical experiment addressing a culturally sensitive and life-threatening question.

"We really learned something from it, because he used the right design — and the right design protected us. Fisher should get credit for leading the way with an experiment protected by randomization — which also protects the results even if people cheat prior to the randomization."

— biostatistician D. M. Stabilein, of EMMES Corp., by phone
Danger and Waste Seen in New Genetics

Boston

Critics of the new genetics presented a wide range of objections at the conference here on this technology's ethical implications. Opponents — like proponents — bring their own points of view to this swirling controversy.

Conference participants thus were forced to sort out for themselves which objections seem substantive, and which, rather, appeared to be restatements of ideological or political points of view.

Current enthusiasm for genetic diagnosis and therapy was denounced as "a bad thing," by retired Harvard biologist Ruth Hubbard, Ph.D., who represents the Cambridge, Mass.-based Council for Responsible Genetics.

Her reason:

Focusing on genetics, and the possibility of preventing or treating genetic illnesses in the future, shifts professional and public attention away from current, and more critical social needs, such as improving the delivery of prenatal care. What is more, Hubbard asserted, social health factors are more important in the long run than health strategies that focus on genes, individuals, or families.

Problems Neglected

Genetics, she charged, usually does not increase people's control of their lives; rather, it often diminishes their sense of control. Genetic information, Hubbard said, "undermines the social contracts that are embedded" in the social and economic networks within which people live.

Her critique was seconded, and extended by social psychologist Adrienne Asch, Ph.D., of Boston University. She objected angrily to a simulated genetic counseling session in which the counselor's opening statement was: "We know we all want our children to be healthy, and we all want them to be happy..."

Discrimination Dissed

In this exchange, "health" and "happiness" were falsely equated Asch declared, later, in a phone interview.

"Having a disability," she explained, "doesn't mean you're unhealthy." Contrary to what the counselor implied, Asch said, people with disabilities are, or can be, "normal." But the counselor's implication was that by being disabled, you are not normal — and "that is discriminating."

"It's discrimination," she continued, to say as the counselor did, "'You don't want to have a disabled child, of course!'" These words, Asch said, are "value-laden" and cruel.

"This is about cruelty!" she said.

Asch, who described herself as "blind," said it is all right to say to a couple that you both are carrying a recessive gene for, say, cystic fibrosis (CF), and to ask if they want to know more about that disease. But it is cruel and discriminatory to start with the value judgement that CF babies are unhealthy, likely to be unhappy, and thus probably should be aborted.

Geneticists Called Passive

The specter of a new eugenics movement, and the racism and discrimination that it carried to the fore in the U.S. and other democratic countries, as well as in other democratic countries, as well as in other democratic countries, as well as...

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Yes. But the panelists offered only glimmerings of what this might consist of, and how it might be put into place.

The right not to know, and not to even be tested evoked the strongest support as a new ethical precept. There is an urgent need "to preserve individuals' right not to know information," asserted attorney Michael S. Yesley, J.D., of the Los Alamos National Laboratory, in New Mexico, who coordinates the program on Ethical, Legal, and Social Implications (ELSI) of the HGP. It is important, he said, "not to force people to get testing when there is no intervention" for a bad prognosis.

No More Unknown Soldiers?

Yesley said later in an interview:

"It is necessary to ignore some things in order to live in tranquility. What genetics can do is to force knowledge on us."

Yesley added, the right not to know "is where privacy begins."

He and other experts warned, however, that this privacy will be harder to preserve than may be imagined — and could be unattainable. Laws are being drafted, at all levels of government, to ban unauthorized access to genetic data in medical records and in the large and growing number of genetic data banks. But they may not suffice. The state of Virginia, Reilly noted, already has DNA data on 100,000 convicted felons. The courts have not objected.

The Department of Defense (DOD), meanwhile, is collecting blood or other specimens and the genetic identifiers they contain from all military personnel in a data bank. The purpose: To be able to identify even badly decomposed combat casualties — and so eliminate Unknown Soldiers, Yesley said.

The data is being withheld from other federal agencies, such as the National Cancer Institute — which might make good research use of it — he added. But there is no guarantee this protection will endure.

Threats to one's wish — or right — not to know can come from various sources.

Family Is Involved

What if, for example, an insurance company offers a policy predicated on a negative test finding for, say, Huntington's disease (HD)? Geneticist Kimberly A. Quaid, Ph.D., of the University of Indiana medical school in Indianapolis, pointed out that if a person discovers through this test that he or she carries the HD gene — which is a dominant lethal, and can't now be blocked — this also reveals information about one's siblings. But they may not want to know it — and may not want their spouses, kids, employers, or insurers to know either.

The present ethical paradigm in medicine focuses on two individuals, a doctor and a patient. But in informing a client about his or her genetic status, a counselor — who is not as...
Video Explores
Gene Tests’ Painful Burden

A video documentary, called "Burden of Knowledge: Moral Dilemmas in Prenatal Testing," dramatically highlights the major changes genetic testing has wrought in women and their families’ lives. The tape, made by independent producer Wendy Conquest of Dartmouth’s Ethics Institute, in Hanover, New Hampshire, follows several women who have undergone amniocentesis for the prenatal diagnosis of Down’s syndrome, spina bifida, and other severe birth defects.

Amniocentesis was introduced a quarter century ago, predicated on the availability of abortion to prevent the birth of afflicted infants. Women who accept this option presumably feel more relief than grief in the long run.

But, as Conquest’s video shows, this can be a wrenching decision. Some women, what is more, are not willing to exercise the choice for abortion because they are pro-life or possibly for other reasons. They thus are burdened with the knowledge of the fetal diagnosis throughout the remainder of their pregnancies, as well as with the affected infant thereafter.

Run Is Extended

"Burden" was scheduled for two workshop presentations at last month’s new genetics conference here. By popular demand, however, two extra showings were needed. All were well attended.

This interest suggests that the burdensome knowledge that women are given, sometimes more or less against their will, is of deep concern to genetics counselors and other participants and critics of the new genetics.

"All of the feelings women have during pregnancy are changed by prenatal testing," one woman declares in "Burden." Another says: "You’ve created the anxiety by creating the test."

Later, a woman complains: "I think we have more information than we want — and all of it is based on fear."

Most women do choose abortion. But the video depicts some who accept the burden of knowledge — that their unborn children are affected — but nevertheless choose to continue their pregnancies. The intense suffering and damaged lives that result are painfully depicted.

A pro-life woman — whose husband is a Baptist minister — decides to continue her pregnancy with a fetus she knows is afflicted with spina bifida. The camera shows the family three years later. The child can’t walk yet, and is incontinent of urine and feces, according to producer Conquest. The mother says she’s embarrassed by the child’s frequent assertions that he “hates Jesus.”

Why?

"Because he pulled the lever that made me go ‘round and ‘round, and when I came out, I couldn’t walk,"' the mother quotes her son saying. "Jesus could walk — and I couldn’t.’’

Doctor Decries Suffering

A physician is quoted, criticizing these women’s decisions: "You always should act," he says, "in favor of less, rather than more suffering." In context this would mean opting for the abortion in the short term, to prevent long-term pain and suffering.

But another voice offers a contrary point of view: "Along with the right to know is the right not to know."

Prenatal genetics tests are now available for a handful of diseases. But biotech companies are working feverishly to produce screening tests that might be used to identify 50 to 100 or more genetic defects from a single specimen of amniotic fluid or placental blood.

One estimate tossed out at the conference here was that for every woman burdened by discovering through these tests that she is carrying a genetically impaired baby, 99 others would gain the knowledge — and relief — of knowing that their unborn babies are not afflicted.

Distribution arrangements for the 54-minute video are being completed, Conquest said late last month by phone. Meanwhile, call her for information at 603-646-1263.

We think it is cruel — to everyone — to continue a pregnancy that will deliver a baby burdened with severe disabilities. It is not a contradiction to love and respect handicapped people on the one hand, and prevent the conception or birth of others who will be similarly burdened.

You can honor and respect war heroes without starting more wars.

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Tay-Sachs...

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another. The gene is recessive. So the disease occurs only when both father and mother are carriers. One in four of their offspring, statistically, will be afflicted.

Method Explained

The orthodox community in the U.S. and Israel developed the preventive program, called Dor Yeshorim in Hebrew, to prevent these births; its director, Rabbi Joseph Ekstein, of Brooklyn, N.Y., described it at the new genetics meeting here:

Teenagers provide a specimen of their cells, which is assayed for the mutant Tay-Sachs gene. But the results are never told directly to the at-risk individuals, and they do not get — or need — genetics counseling, the rabbi said.

Each teen is assigned a number; Ekstein explained. Later, when dating, two would-be spouses exchange code numbers. Separately or together, they phone a Tay-Sachs hotline. They put in their codes, and are told just one piece of information: whether or not their union could produce a fetus with Tay-Sachs. (The program recently added testing for two or three other severe inherited diseases.)

The answer is yes or no — if you marry, your children will or will not be at risk. If they are at risk, both are carriers of the mutant gene.

Plans Must Be Cancelled

To avoid the risk, the couple, of course, must give up their relationship. Or, if they go ahead, they face the choice of whether to have prenatal diagnosis and, possibly, an abortion. Or, in vitro fertilization (IVF) with donor sperm or ova.

Unanswered are the questions of whether other, tightly-knit groups will want to create similar prevention plans for indigenous high-risk diseases. And whether a comparable system would work in a wider sphere.

Meanwhile, interest in Tay-Sachs recently has led to another, wholly novel preventive scheme for couples at risk who abhor abortion: The inventor, reproductive biologist Gary Hodgen, Ph.D.; of the Jones Institute for Reproductive Medicine, in Norfolk, Va., described it here:

First, sperm is obtained from the man, and ova from the woman, using nonstandard methods. Fertilization takes place in a petri dish.

Pre-embryo Tested

The pre-embryos that result are allowed to develop to between 4 and 12 cells. One or two of these cells are then removed from each pre-embryo. The cells’ DNA is isolated, and amplified using a method called polymerase chain reaction (PCR). This yields enough DNA to determine if the pre-embryo is afflicted with Tay-Sachs (two mutant genes), is a carrier of Tay-Sachs (one mutant gene), or normal (no Tay-Sachs mutation).

Studies have shown that removal of one or two cells does not harm the pre-embryo, Hodgen said.

The normal embryos are then implanted in the woman’s uterus, as in standard IVF. Afflicted embryos are destroyed or, if carriers, may be held in reserve.

The first couple that tested this method are Cajuns, from DeRidder, Louisiana, a farm town. The Tay-Sachs carrier rate in this area has recently been found to be twice as high as among orthodox Jews, and 25 times higher than in the population at large.

Parents Say Yes

The Norfolk team approached David and Renee Abshire, members of the pro-life Assembly of God, who had lost their first child to Tay-Sachs. The couple had vowed not to have another baby until they could be certain it would not be afflicted. The Abshires needed two years to make up their minds: They began the experimental treatment, in Norfolk, last year.

Four embryos were obtained, Hodgen reported here; three were normal when tested, and were implanted in Renee. One survived and developed. Renee’s “miracle” girl, Brittany, was delivered on January 26.

Tests confirm: She does not have Tay-Sachs.

Other IVF researchers at the Boston meeting said they were gearing up to offer Hodgen’s technique for Tay-Sachs — and for other genetic diseases.

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ethically bound as a physician — is exposing information that may be distressing and damaging to a wide circle of people.

The technical paradigm of genetic testing thus demands a new — and thus far unformulated — ethical paradigm that respects the privacy rights of this wider circle of people.

Industry Has Key Role

Conflict may be heightened by the fact, acknowledged by several speakers, that the genetic medicine field currently is being rapidly advanced by commercial interests. Gene therapist James M. Wilson, M.D., of the University of Pennsylvania, said that the “whole direction of the field is now driven by commercialization,” based on principles not always related to the “public good.”

The academic research community, Wilson said, can’t carry the technology directly to the public — it does not possess the resources and expertise to do so. Industry does.

The inducements for testing also are clear: One estimate cited is that recent discoveries of mutant genes that predispose people to breast cancer and colon cancer could lead — through close patient monitoring and early intervention — to saving 10,000 American lives each year.

This, however, remains to be proven.

Interventions Lag

Many of those tested will be relieved to learn that they probably will escape a hereditary cancer that has claimed other family members. But some will be burdened with the knowledge that their children may be carriers of the disease.
Somalian Fights Genital Mutilation With Her Wrenching Film ‘Fire Eyes’

Beyond the physical and emotional horror of it, female genital mutilation (FGM) is an extreme case of a more widespread conflict. This is the struggle between individual freedom and cultural hegemony — between personal autonomy and communal proscription.

Sexual pleasure is physically proscribed, and pain is prescribed by the mutilative practices that affect tens of millions of women in Africa and the Middle East (PROBE, Feb., ’93). We recently interviewed a victim who is now boldly fighting against this cruel practice. She is Somalian Soraya Mire (say me-RAY), 32, a long time Californian and film maker, who graduated from the UCLA film school and Domaine University, in Grenoble, where she studied political science.

Pain Depicted

Rapidly — and deservedly — Mire is becoming a celebrity because of her powerful first film, “Fire Eyes.” It depicts, graphically, the pain, terror — and permanent loss — that results from unsterile amputation of the clitoris and erotically responsive labial tissues.

“Something’s missing!” Mire declares in the film. “I’m not whole. I’m not complete!” The “fire eyes” of the title, she adds, is the expression of pain and of anger that she and others like her have experienced. “It kills the spirit of a child,” she says. “You see it in her eyes!”

Others Cry Now

Making the film was a “healing process,” Mire says. “Now other people cry for me!’’

The film, in Somalian and English, has been shown at festivals in Sundance, Utah, New York, and elsewhere, winning...continued on next page

Horror Recalled

“I knew exactly what was happening. More than the pain — it was the sound of that scissors cutting some part of my body. . . . After that, my life just changed because they did it so severely!” — S. Mire in “Fire Eyes”

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eedge that they appear destined to develop these cancers — and that this knowledge outstrips methods currently available to monitor and treat them at an early stage.

“The private sector has identified gene hunting as the front end” of the process for the development of diagnostics and medical interventions,” pathologist Robert M. Cook-Deegan, M.D., of the Institute of Medicine, in Washington declared. He said that $150 million of private funding was spent on this endeavor last year; a similar amount was spent by the federal government.

From the research point of view, others added, all knowledge is good. But from the personal or societal points of view, it may not be.

Much of the pressure for genetic tests and therapy, several speakers said, comes from the public. But people are being led on, and misled, about how much benefit genetics can provide, they added (See story, p. 4).

Perspectives Differ

A major conflict has arisen between parents and children, geneticist Reilly said. Parents want to use genetic tests to decide what kind of kids they will have. Children who suffer from now-preventable disabilities say this disrespects them, and is discriminatory.

The disabled, Cook-Deegan explained, see this as an effort to prevent future ‘‘me’s’’ from being born. So, he said, it is hard

to convince them that there is no contradiction between providing care for disabled people who are living now, and preventing the birth of others like them in the future.

Those whom medicine and society regard as “disabled” reject this stigma, several speakers pointed out. Some of them want to use the new genetics precisely to reproduce themselves just as they are.

Pirandello Cited

This and the many other conflicting points of view have transformed the new genetics into a Pirandello-like drama, one speaker declared. As in Pirandello, each participant’s autonomy and perspective deserves respect.

In this context, reproductive biologist Gary Hodgén, Ph.D., who runs the Jones Institute for Reproductive Medicine, in Norfolk, Va., was asked what he would do if two married Little People, who are defined genetically as achondroplastic dwarfs, asked him to use the methods he has developed to help them conceive a short-statured child.

This choice already is within the realm of possibility, Hodgén replied (See story, p. 1). If asked, he said, he would use his methods to give the parents a “short stature” baby.

Asked what he would not do, Hodgén said, he would not use his methods — which can assess a human embryo before it is implanted in the mother — to select a baby of one sex or the other.

“The wishes of the family have to be dominant,” Hodgén said, reflectively. But society’s need — in this case, for equal respect for both sexes — also must play an ombudsman role in these decisions.

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rave notices. It may be released commercially, and Mire is raising money to translate it into Sudanese and other African languages. She hopes to entice the woman — who perpetuate the practice on their daughters — and the men (whose pleasure also is diminished) not to impose FGM on their children.

In the film, Asha, a 32-year-old wife and mother, says:

This is our ancient custom that we won't let go. They circumcised my mother ... my great grandmother, and this must follow in the young generation ... . If I don't circumcise my child, she will only make the man run away from her.

Ali, a Somalian man, says:

In our tradition, a woman gets more trust when she's stitched ... . In the morning, leaving your apartment, would you leave your door open, or locked? A woman's not a door. But she's property to someone. She's my property ...

Much suasion will be needed to change this gruesome custom, Mire said, and she is committed to doing what she can. She has a sparkling, charismatic personality that attracts people's interest. She lives in Los Angeles. But on a recent Manhattan walk, with a lunch stop at a Senegalese restaurant on Sixth Avenue, she was greeted by a dozen people from the film, media, and African expatriate worlds.

If Soraya Mire keeps on at this rate, she and the growing numbers of women — and men — who have joined her crusade may one day succeed. We hope they do!

"Fire Eyes" is being shown at film festivals, and may soon be released commercially. It's gripping. Watch for it!

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