SPECIAL REPORT

Casual Eugenics

Prenatal screening has become a death sentence for the disabled.

Valerie Schmalz

Look around your neighborhood, in the grocery store, at the YMCA. Do you ever see babies and children with Down syndrome anymore? Do you ever see children with cystic fibrosis? Children with disabilities in wheel chairs?

If the answer is no, there is a reason, and it is chilling: a high percentage of unborn children with disabilities are now aborted.

Hospital statistics suggest that 90 percent or more of children prenatally diagnosed with Down syndrome are aborted. Also aborted at high rates are unborn children prenatally diagnosed as having cystic fibrosis, Tay Sachs disease, sickle cell anemia, spina bifida and other neural tube defects. And with each passing year the conditions cited to justify therapeutic abortion grow more superficial. Unborn children with club feet, cleft palates, webbed toes, and extra fingers are among the aborted.

COURTESY OF SPINEFEX PRESS

■ **Melinda Tankard Reist, author of *Defiant Birth: Women Who Resist Medical Eugenics***

“It comes down to cold hard economics,” said Australian Melinda Tankard Reist, author of *Defiant Birth: Women Who Resist Medical Eugenics* (Spinefex Press, 2006), 19 tales of women who gave birth despite overwhelming pressure to abort. “Abortion has become a bargain in a society which sees people with disabilities as costing the rest of us too much money.”

Abortion, presented as a “choice” and “right” for pregnant women, is becoming more like a duty once they are confronted with test results that show imperfections in their children, Reist and others told *Catholic World Report* in a series of interviews.

A paper published by the *American Journal of Medical Genetics* in 2000 concluded that aborting children with birth defects could save Americans about $2 billion a year. “They push it,” one mother said of her health maintenance organization (HMO). “They honestly look at it as preventative medicine. They’re very nice people there. It’s just policy, basically.”

“A woman in London said she was pressured to abort because her child had a fingernail abnormality. Who of us is safe?” Reist said. “I keep hearing from women all the time. I think regardless of anyone’s politics on abortion, no woman should be treated like this.”

The British Office for National Statistics reported that between 1996 and 2004, 20 babies were aborted for clubfoot, according to the London-based *Daily Mail*. The problem, correctable without surgery, causes the foot to point downwards and in severe cases causes a limp.

(Ironically, most disabilities occur after birth with some estimates of after-birth disabilities as high as 80 percent. The American Association of People with Disabilities estimates that 50 million Americans suffer a disability, or one in five Americans.)

The assumption that a birth defect will lead to the termination of a child is so pervasive that many advocates for the disabled, who normally support abortion, are decrying the new eugenics.

“A policy of prevention-by-screening appears to reflect the judgment that lives with disabilities are so burdensome to the disabled child, his family, and society that their avoidance is a health care priority,” wrote Yeshiva University professor of bio-ethics Adrienne Asch and David Wasserman, in a 2006 essay published on the American Medical Association website. Asch described herself as “pro-choice” in an interview with *CWR*.

“Many people assume that people with disabilities would want to spare future generations from the difficulties we had to endure,” observed Laura Hershey in a 1999 column on her blog *Crip Commentary*. But, she wrote, “Attempting systematically to wipe out disabilities is the wrong solution. Instead, society should commit itself to removal of these barriers, and to full equality for people with disabilities.”

Initiatives to provide accurate information about prenatally discovered conditions, as well as parental support, have sprung up in response to the new eugenics, among them Morning Light Ministry, the websites www.benotafraid.net and www.prenatalpartnersforlife.org, and the Institute for Fetal Health at Children’s Memorial Hospital in Chicago, said Victoria M. Thorn, executive director of the national office of Post Reconciliation and Healing in Milwaukee.

“I’ve dealt with women who have had an abortion for Downs and afterwards have met a Downs child and have said, ‘Oh my God, I had no idea, we could have raised a Downs child,’” Thorn said.

A Harvard Medical School researcher published two significant quantitative studies last year which found that physicians relay the Down syndrome diagnosis to parents in an alarmist manner and give them distorted information. The diagnosis is “frequently inaccurate and very often an offensive portrait of what Down syndrome is like,” said the studies’ author Brian Skotko, MD. Down syndrome is the most common chromosomal abnormality in humans, Skotko said.

Skotko’s largest study included 985 mothers who learned of their child’s condition after birth and 141 who learned via prenatal diagnosis. In response to such studies, Senator Ted Kennedy, D-Massachusetts, and Senator Sam Brownback, R-Kansas, co-sponsored the Prenatally Diagnosed Conditions Awareness Act this year. The legislation would appropriate $25 million to "increase the provision of scientifically sound information and support services" for families who receive a diagnosis of a condition such as Down syndrome, cystic fibrosis, and spina bifida.

FISCALLY RESPONSIBLE ABORTIONS?

A measure of the cultural acceptance of abortion aimed at people who are disabled is the publication of matter-of-fact quantitative analyses of its potential to save money for society.

A study published by the *American Journal of Medical Genetics* in 2000 addressed the fiscal impact of a ban on second-trimester abortions for "prenatally diagnosed abnormalities" at one hospital in Michigan. "Attempts to reduce abortion availability have generally ignored the fiscal impact," the paper's authors state, noting in their introduction that the extrapolated cost of a ban on abortion for children with defects would cost the United States approximately $2 billion in 1992 dollars.

A measure of the cultural acceptance of abortion aimed at the disabled is the publication of matter-of-fact quantitative analyses of its potential to save money for society.

The study concluded that each Down syndrome child aborted saved $451,000 in lifetime medical costs, while aborting a child with spina-bifida saved $294,000, and a child aborted for cleft palate saved $101,000.

The paper listed by cause the 514 children aborted in the second trimester for birth defects at a Michigan hospital over the course of eight years, 1990-1997. They included 84 for Down syndrome, 45 for spina bifida, 26 for heart problems, and even eight for urinary obstruction.

Kaiser Permanente of Northern California, a health maintenance organization, studied the fiscal impact of offering cystic fibrosis (CF) screening to couples where at least one parent was Caucasian. Of 56,000 people screened, nine fetuses with a severe CF mutation were discovered and all nine were aborted, Kaiser reported at the 2003 annual meeting of the American Society of Human Genetics.

"The bottom line is that in our system, at least, cystic fibrosis screening pretty much pays for itself," said Dr. David R. Witt, the director of the CF screening program at the meeting, according to an *International Medical News Group* report. He estimated that the lifetime cost per child would have been $675,000, not including non-medical costs such as parents' lost time from work.

A paper published in the September 2005 edition of the *Journal of Pediatrics* estimated that birth rates of children with cystic fibrosis have dropped about a third in Canada since the 1989 discovery of a prenatal test for cystic fibrosis. The paper concluded that testing expansion might lead to a further drop. The American College of Obstetricians and Gynecologists recommended in 2001 that all fetuses with at least one Caucasian parent be tested for CF. In practice, because of the difficulty of ascertaining ethnicity, the CF test is offered to almost all expectant mothers, said Joan A. Scott, Deputy Director of the Genetics and Public Policy Center of Johns Hopkins University in Washington, D.C.

"We are using these technologies to search and destroy people with disabilities," Reist said. "We're blaming women for having these children."

NORMALIZING PRENATAL TESTS

Standard care recommended by the American College of Obstetricians and Gynecologists includes a battery of tests to determine the health of the mother and the unborn baby. But most of the tests of the baby are for conditions that cannot be treated.

"Across the board, these technologies are part of the standard prenatal package and often women don't know what the test is for," Reist said. "This is the maternally acceptable thing you do. Women are often shocked to discover that the option offered is abortion."

Last November, the *New England Journal of Medicine* published news of a first trimester screening test that can reliably identify fetuses likely to have Down syndrome at 11 weeks gestation. The screening will make it easier to abort, said Fergal D. Malone of the Royal College of Surgeons in Dublin, who led the study, according to the *Washington Post.*

"By the time you're 20 weeks pregnant, most women will be feeling fetal movement. We wouldn't want to underestimate the psychological or emotional difficulty of undergoing pregnancy termination that late," Malone told the *Post*.

Estimated Average Lifetime Costs Averted for Selected Conditions at Hutzel Hospital in 1992 U.S. Dollars

	Total 2nd trimester terminations for birth defects (1990–1997)	Average number of cases per year	Average lifetime cost per new case in 1992	Est. lifetime cost for an average year of patients treated
Down syndrome	**84**	10.5	$451,000	$4,735,500
Spina bifida	**45**	5.6	$294,000	$1,646,400
Cleft lip or palate	**13**	1.6	$101,000	$161,600
Renal agenesis	**11**	1.4	$250,000	$350,000
Omphalocele	**11**	1.4	$176,000	$246,400
Urinary obstruction	**8**	1.0	$84,000	$84,000
Diaphragmatic hernia	**5**	0.6	$250,000	$150,000
Lower limb reduction	**1**	0.1	$199,000	$19,900

■ **A study published by the *American Journal of Medical Genetics* in 2000 addressing the fiscal impact of a ban on second-trimester abortions for "prenatally diagnosed abnormalities" at one hospital in Michigan.**

Johns Hopkins' Scott said none of the tests should be given without full informed consent from the mother. "Some obstetrical practices are very good about doing the informed consent thing and others are so overburdened (that they say) 'you don't need to worry about this. If something comes back, a problem, then we'll talk about it,'" Scott said.

In the first trimester, a blood test—called triple screen or the more recent quadruple serum screen—tests for the probability of a neural tube defect or chromosomal or genetic abnormalities, Scott said. With the new first trimester screening, which is not yet standard, a blood test and an ultrasound identified 87 percent of Down babies, in a study of more than 38,000 women, the *New England Journal of Medicine* reported.

For a result that is close to statistically certain, one of two follow up tests is used after the screenings. Amniocentesis is usually done at the beginning of the second trimester at 15-16 weeks while chorionic villus sampling (CVS) is usually done between 8 to 11 weeks gestation.

With amniocentesis, a needle is inserted into the uterus to extract amniotic fluid while with CVS, usually, a catheter is inserted and some cells from the placenta extracted. The risk of miscarriage is about 1 in 200 for amniocentesis while CVS’s risk is about 1 percent, according to medical statistics, Scott said. Amnio risks may be much lower because the practice has been common since the 1980s, while the risks of CVS are higher since fewer doctors know how to perform the procedure well. Any mother choosing CVS should ask for the miscarriage statistics of the person doing the test, Scott said.

WHY TEST?

The main benefit of prenatal tests, when parents are not going to abort the baby, is information, Scott said. In a few cases, the information can lead to important pre-natal treatments, notably in instances of HIV and spina bifida.

“We really are a society that is reaching a consensus that it is socially acceptable to abort a child with a disability,” says Schiltz.

With spina bifida, among other interventions, doctors will choose to deliver the baby via Caesarean section at a facility where the child can be whisked into surgery to close the open spinal cord. At Children’s Hospital of Philadelphia, a study is underway on the effectiveness of in-utero surgery for repairing spina bifida, Scott said. Neural tube defects are spotted via a blood test and then a follow up ultrasound. Amniocentesis will alert to related conditions such as Trisomy 13, another chromosomal condition that usually leads to early childhood death, Scott said.

An HIV blood test is standard for pregnant women after they first visit the obstetrician. Mother-baby transmission risk is reduced to 2 percent by a variety of drug treatments prenatally and after the baby is born by abstaining from breast-feeding and delivery by C-section.

For other conditions, parents who don’t choose abortion use prenatal tests as an occasion to prepare earlier.

Elizabeth R. Schiltz, associate professor of law at the University of St. Thomas School of Law, found out via amniocentesis that her third child, Petey, now 2, had Down syndrome.

“I was glad I was able to go through what really was a very intense grieving process. I was glad I could go through that before he was born,” said Schiltz, who wrote an essay in *Defiant Birth*.

Down syndrome testing has been standard for women 35 and over for decades, while testing for cystic fibrosis first became possible in 1989. Genetic tests for Tay Sachs disease are available to Ashkenazi Jews, and tests for sickle cell anemia are generally offered to African Americans and those with Mediterranean backgrounds. Nearly 1,000 genetic and chromosomal tests are available, but typically a pregnant woman is only offered those tests if an inheritable disorder is in the parents’ background, Scott said.

THE PRESSURE TO ABORT

Many mothers say doctors leave them with a tacit message once they identify conditions such as Down syndrome or cystic fibrosis in unborn children. The message is: abort them.

“We really are a society that is reaching a consensus that it is socially acceptable to abort a child with a disability,” says Schiltz. “It really, really scares me. How are we going to learn what God is if we can only see half his face?”

With a wide-range of tests creating such temptations, some parents opt out all together, noted Madeleine Veneklase. She scheduled the triple screen blood test when she was pregnant at age 44 with her fifth child, Veronica, but then missed the appointment. After Veronica was born, the managed care pediatrician in the delivery room approached her while her husband, Chris, had popped out looking for a camera. Veneklase recalled that the pediatrician asked her: “‘At your age, why didn’t you have an amnio?’ I said, ‘No, my husband and I decided it was not necessary.’ ‘Well, your daughter is showing some signs of Down syndrome, I’m sorry,’ the pediatrician said.

“I didn’t feel one bit of a letdown. It must have been the Holy Spirit. I was so angry. It was that sickening attitude that this was a subhuman! My reply was, ‘My husband and I feel God gives us the children he wants us to have, so don’t apologize, we’re not sorry!’”

PRENATAL TESTING: WHAT THE CHURCH TEACHES

In the 1987 document *Donum Vitae* or *The Gift of Life*, issued by the Vatican Congregation for the Doctrine of the Faith, the Catholic Church answers the question: “Is prenatal diagnosis morally licit?”

“If prenatal diagnosis respects the life and integrity of the embryo and the human foetus and is directed towards its safeguarding or healing as an individual, then the answer is affirmative,” says the document, signed by its prefect, Cardinal Joseph Ratzinger, now Pope Benedict XVI.

But prenatal diagnosis can never be used as a trigger to abortion, *Donum Vitae* emphasizes: “A diagnosis which shows the existence of a malformation or a hereditary illness must not be the equivalent of a death-sentence.”

Veronica and Regina, the daughters of Madeleine and Chris Veneklase

COURTESY OF THE VENEKLASES

What does this mean for those parents who are sitting in the doctor’s office, trying to decide which of the many tests recommended by the American College of Obstetricians and Gynecologists they should select?

“Any test oriented toward the child would be morally acceptable,” said Rev. Tadeusz Pacholczyk, Ph.D., director of education for the National Catholic Bioethics Center in Philadelphia.

The Church teaches that directly willed abortion, no matter what the circumstances, is “gravely contrary to moral law,” and attaches the canonical penalty of excommunication to “this crime against human life,” according to the *Catechism of the Catholic Church*.

"You might want to do testing to see if a child will be affected with a disease to prepare yourself as a couple," Rev. Pacholoczyk told *CWR*. "That would be legitimate if the couple is unbending in their orientation not to go down the path of abortion. What actually happens in the real world, when there is a defect – a couple who had previously espoused a pro-life position may sometimes buckle and go forward with an abortion. This testing opens the door to certain temptations that are at times better avoided."

The Catholic Health Care Association, which is the association for Catholic hospitals in the U.S., follows the directive of the U.S. Conference of Catholic Bishops and complies with *Donum Vitae*, said spokesman Fred Caesar.

THE IMPLICATIONS FOR THE LIVING

The new eugenics affects not just the unborn who are disabled; it also raises a foreboding question for the people with disabilities who are living: Will society grant resources to them more grudgingly now that it considers disability a "preventable" problem? Will the culture of health care and insurance tilt against parents who make the "wrong" choice?

"Our public policy must be crystal clear that no family will ever be penalized for choosing not to have prenatal diagnostic tests or for choosing to go forward with the pregnancy after a disability has been prenatally diagnosed," said Andrew J. Imparato, president of the American Association of People with Disabilities, in 2004 testimony before a Senate subcommittee.

"Similarly, we need to protect medical professionals from being penalized or held liable in the event their patients elect to avoid prenatal tests or choose to move forward with a pregnancy where a disability has been prenatally diagnosed," Imparato said.

Bioethicist Asch's book, *Prenatal Testing and Disability Rights*, edited with Erik Parens (Georgetown University Press, 2002), is a collection of essays on this topic and drew particular notice because of its singular lack of agreement on whether aborting for a disability is permissible.

"Prenatal diagnosis—through amniocentesis, chorionic villus sampling, or pre-implantation genetic diagnosis (PGD); for Down syndrome, cystic fibrosis, female gender or blue eyes—needs to be seen for what it is, or more importantly, what it is not," wrote Asch and Wasserman, JD, in an op-ed on the AMA website this year.

"It is not a medical procedure—that is, a procedure intended to protect or restore an individual's physical or mental health. Rather, it is typically a procedure to identify unwanted organisms."

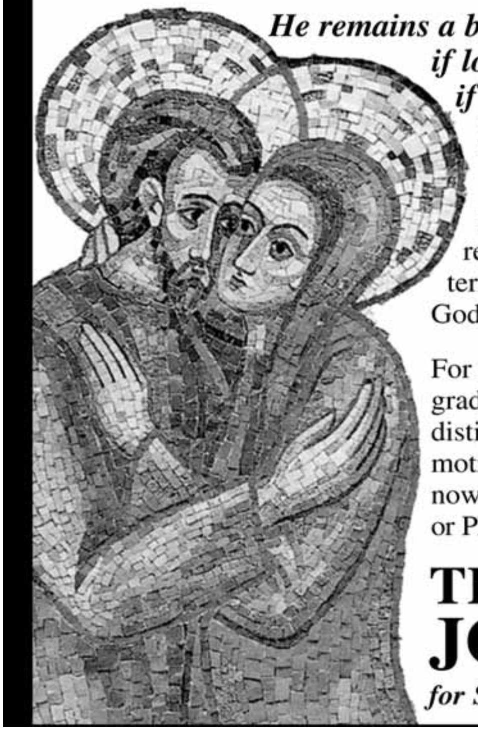
Or, as associate law professor Schiltz, who is pro-life, says, "My having Petey is a sin according to some people."

Fertility pioneer Robert Edwards, who 25 years ago created the first test tube baby, predicted at a 1999 international fertility conference, "Soon it will be a sin for parents to have a child which carries the heavy burden of genetic disease. We are entering a world where we have to consider the quality of our children."

EUGENICS IN THE LAB

Fertility technology is another tool of eugenics wielded against people who are disabled. In-vitro fertilization is not only used by infertile couples but also by fertile ones who seek to avert the possibility of "defective" children through the proactive use of pre-implantation genetic diagnosis (PGD) while embryos are still in the Petri dish. Doctors and geneticists increasingly recommend PGD as a means for fertile couples to ensure that a healthy embryo is implanted.

In recommendations published this year, the European Societies of Human Genetics and Human Reproduction and Embryology suggested that PGD be



offered to families with inheritable disorders. If the family wants to use PGD to choose the sex of the child, and presumably discard embryos from the unwanted sex, "it should be limited to family balancing"— that is, obtaining a child of the opposite gender of the family's existing child—the genetics society recommended.

PGD is unregulated in the U.S. But it is banned with no exceptions in Austria, and banned except for medical reasons in Germany and Switzerland. It is also banned, except to avoid gender-related inherited conditions, in Australia, Canada, France, India, Japan, the Netherlands, and the United Kingdom, according to a June 18 *Associated Press* story.

In the U.S., some hospitals screen in-vitro embryos to choose a child's gender, said Skotko, author of the Harvard study on Down syndrome. A recent study estimated that in India 10 million female fetuses were aborted in the last 20 years at a rate of half a million a year despite a 1994 law prohibiting the practice, according to an article published in January in the British medical journal *Lancet.* China's one-child policy and the technology of ultrasound and access to abortion are blamed for the country's girl-boy imbalance of 100:116.

There has not yet been a nationwide study of the relationship of prenatal diagnosis and abortion of children with disabilities, Skotko said.

Johns Hopkins's genetics policy center deputy director Scott said the use of PGD to screen out inheritable disorders is growing. And it is also increasingly used for mothers undergoing in-vitro fertilization since repeated miscarriages are often due to chromosomal problems in the baby, she said.

So-called "savior siblings" are also chosen via PGD as parents discard embryos in the search for a second child who will have the correct blood or tissue type to save an already born child sick with leukemia or other diseases, said Catholic bioethicist Rev. Pacholczyk. "These technologies of testing very early on humans are finding new ways to impose eugenics more broadly and to further instrumentalize humans," he said.

GENETIC DISCRIMINATION BEYOND THE WOMB?

The prospect that genetic information will accelerate discrimination in the allocation of health insurance, job placement, and government funding has prompted some legislation in the U.S. and around the world.

Forty-one U.S. states have banned the use of genetic information by health insurance companies in providing policies. At the federal level, the Health Insurance Portability and Accountability Act (HIPAA) of 1996 specifically prohibits the use of genetic information to deny group insurance coverage when workers switch from one job to another. (The federal law does not apply to private individuals seeking insurance in the individual market but some states protect those people, according to *The San Francisco Business Times.)*

Colorado disability activist Hershey observed in a 1999 column on *Crip Commentary* that genetic knowledge can be used to find cures, but "is likely to be put to other, more insidious, uses—such as denying health insurance, even jobs, to people whose genes predispose them to medical problems. Another threat is the implementation of eugenic policies to 'weed out' certain types of people from the population."

Such use of genetic data is already happening.

In Great Britain, life insurance companies in some instances can use genetic test data on Huntington's chorea in deciding whether to insure. This disease, which notably killed the balladeer of the workers' rights movement Woody Guthrie, is late onset and physically and mentally degenerative before eventual death. Guthrie wrote what many consider the United States' unofficial anthem, *My Country 'Tis of Thee*.

In Germany, an administrative court in 2001 reinstated a bank employee who had been fired without notice on the basis of secretly obtained DNA. The man, after having been suspected by the bank management of authoring an anonymous letter executives considered insulting, was invited to an event where food and drink were served. The executives then collected his DNA and sent it out for comparison.

The collection of genetic data, and whether once collected it can be safeguarded, is no longer the topic of futuristic movies and apocalyptic doom-mongers.

In June, Kaiser Permanente announced plans to request DNA material from up to 2 million adults in Northern California. A spokesman said Kaiser is among a number of health-care organizations around the country hoping to build large DNA databases in the hopes of finding genetic links to various diseases, the *San Francisco Business Times* reported.

The *Business Times* editorialized on June 16 that while the project "is being undertaken with the best of intentions," the risk of assembling so much data creates "plenty of potential peril, both for Kaiser and the privacy of millions of its members."

Germany's government, because of the country's Nazi history, is particularly sensitive to issues of genetic profiling. Nevertheless, abortion for birth defects is allowed up to the ninth month, pro-life Christian Democrat Mechthild Löhr told *CWR*.

A special study group commissioned by the German Bundestag examined the issue and noted that genetic information is often given too much weight because genes do not predict everything, and even the most accurate tests can be wrong. In Germany, there are no specific statutory provisions for genetic counseling and diagnosis, even though the topic has been discussed exhaustively since the 1980s. In its findings, the Bundestag's special study group noted that genetic testing: "establishes links with ethnicity and hence, involves the risk of racist discrimination"; "may provide a pretext for social stigmatization (employers, insurance companies, partnership bureaus)"; "involves the risk of eugenic discrimination."

The sick irony of the new eugenics is that it destroys society's quality of life in the name of improving it. As Schiltz, the law professor with the Down syndrome son, sees it, society is using technology to erase the colorfulness, diversity and occasions for love God intended.

"What about the quality of life of the rest of us if we don't have people with disabilities in our world anymore?" asks Schiltz. "What a horrible world we would have!"

"God's got a purpose. God wants these people here with us," says Madeleine Veneklase, who takes Veronica, her daughter with Down syndrome, to the grocery store in their home town of Napa, Calif. "She waves at old people. She reaches out to people. She's only 2 years old. Maybe she's the only one who smiled at someone that day." ■

VALERIE SCHMALZ, a former reporter for the Associated Press, writes for IgnatiusInsight.com.
