



WE KNOW ONLY IMPERFECTLY

In his first letter to the Corinthians, St. Paul writes: “Now we see only reflections in a mirror, mere riddles...” Also in the times of St. Paul, the faithful were reminded that they did not have all the answers, for as St. Paul states “we know only imperfectly”.

In his first letter to the Corinthians, St. Paul writes: “Now we see only reflections in a mirror, mere riddles...” Also in the times of St. Paul, the faithful were reminded that they did not have all the answers, for as St. Paul states “we know only imperfectly”. When approaching the challenging topic of this year’s Summer School: “**Why Bioethics?**” and “*the biotechnological issues facing people today*”, there are many among us who may feel at loss. Bioethical questions require insight, knowledge and reflection, and experts and ethicists do not necessarily agree.

When facing issues that seem to go beyond our comprehension, an easy way out may be to say: “I will leave this to people who are wiser than me” or “This is none of my business!” There were times when those who possessed the learning and the power would endorse such an attitude of those whom they considered ignorant! And in fact, there are still a number of societies where people are not given the opportunity to acquire necessary skills to form opinions or where women, for instance, are not given the right to have a say.

Even in so-called “modern societies” there is a tendency to leave a number of questions to entrusted experts. Experts are called in, form public opinion and tend to rule the ground in many fields. It may be difficult to raise one’s voice as a regular citizen because when entering the arena of experts, one may be short of facts and therefore short of arguments. And still there are a number of issues that should not be left to experts only – issues that deal with core questions of every citizen and every human being, questions that may influence both the daily life and the years to come. Among such important issues are bioethical questions.

Bioethical terms hit the headlines. We are confronted with concepts such as IVF, surrogacy, gene therapy, stem-cell research, organ implants, euthanasia, human enhancement, only to mention a few, and know instinctively that every year science is opening a door to new knowledge, new practices and new possibilities that will reshape the conditions of human life. For better, for worse, our lives and the lives of our children and grandchildren will be influenced by decisions that experts and

politicians promote. We have a right to be part of that process.

Not only do we have a right. We also have a duty to become informed and express an opinion. A true democratic society is based upon active citizenship and the participation of individuals. To leave the difficult questions and problems to others may seem like a comfortable and easy way out, but it may have as a consequence that wrong decisions are made. And as it has been claimed: "To remain silent and indifferent is the greatest sin of all." (Elie Wiesel)

Nevertheless, *the rights and the duty* cannot be fulfilled without some insight. No-one can be an expert in every field, but we can all be "enlightened citizens" - conscientious members of our church, workplace, organisations or family, ready to obtain necessary information and facts in order to form and voice an opinion on vital, core issues.

Connected with the need to be informed is the need to accept with humility that a great number of issues often present various solutions. Not everything is black and white. It is important to be open and willing to listen to contradictory arguments. Bioethics is typically a field that may sometimes present visions of new hope; sometimes a feeling of great danger. Regardless of our own attitude, we cannot be a good contributor to a meaningful discussion unless we accept to listen to the arguments of others. "Think for yourself and let others enjoy the privilege of doing so, too!" (Voltaire)

As Catholic women we look to the Church for direction and moral guid-

ance. When the Church speaks up, the main concern is the dignity of the individual and the sanctity of life. But even moral theologians may find that whereas some problem areas may easily be labeled "good or bad" from a Christian point of view, others have shades of grey and are not quickly "classified". The Church as a community of believers has as a mission to be faithful to the teaching of Christ and His Truth, and yet the community cannot claim that no reflection is necessary because its leaders possess the whole truth for all times. We have to recognize, as St. Paul did, that "we know only imperfectly", that we see only reflections of truth and therefore have an obligation to continue searching for the true answers.

With this in mind, we do hope that you will enjoy reading this Magazine- and hopefully feel more informed once you have done so – and then be inspired to participate in our Summer School 2015 in Vienna that will address the issues of the following pages.

Enjoy reading!

Mette Bruusgaard





WHAT IS BIOETHICS?

THE STUDY OF THE TYPICALLY CONTROVERSIAL ETHICAL ISSUES

Bioethics is the study of the typically controversial ethical issues emerging from new situations and possibilities brought about by advances in biology and medicine. It is also moral discernment as it relates to medical policy, practice, and research. Bioethicists are concerned with the ethical questions that arise in the relationships among life sciences, biotechnology, medicine, politics, law, and philosophy. It also includes the study of the more commonplace questions of values (“the ethics of the ordinary”) that arise in primary care and other branches of medicine. The field of bioethics has addressed a broad swathe of human inquiry, ranging from debates over the boundaries of life (e.g. abortion, euthanasia), surrogacy, the allocation of scarce health care resources (e.g. organ donation, health care rationing) to the right to refuse medical care for religious or cultural reasons. Bio ethicists often disagree among themselves over the precise limits of their discipline, debating whether the field should concern itself with the ethical evaluation of all questions involving biology and medicine, or only a subset of these questions.

The term *Bioethics* (Greek *bios*, life; *w*, behavior) was coined in 1926 by the German Fritz Jahr, who “anticipated many of the arguments and discussions now current in biological research involving animals” in an article

about the “bioethical imperative,” as he called it, regarding the scientific use of animals and plants. In 1970, the American biochemist Van Rensselaer Potter also used the term with a broader meaning including solidarity towards the biosphere, thus generating a “global ethics,” a discipline representing a link between biology, ecology, medicine and human values in order to attain the survival of both human beings and other animal species.

Source: Wikipedia

SOME IMPORTANT DATES IN THE HISTORY OF BIOETHICS AND QUESTIONS ARISING

- 1947:** The Nuremberg Tribunal convicts German physicians for committing war crimes under the guise of medical experimentation. (Voluntary consent is essential)
- 1954:** Donation of one kidney from a healthy patient to a relative. (Is it right to subject a healthy person to the loss of an organ even to save life?)
- 1956:** Mentally retarded children in New York State injected with virus to develop vaccine. (Should people incapable of informed consent become research subjects?)
- 1962:** Discussion in regard to the selection of patients for life-saving programmes. (Who should have the access to scarce life-saving technology, and who gets to choose the patients?)
- 1967:** Dr. Christian Barnard from South-Africa transplants a human heart from donor to a patient with terminal heart disease. (Was



the heart donor truly dead? Was the heart taken without the consent of the donor? How to define death?)

- 1968:** Harvard Medical School proposes a definition of brain death, making it easier to harvest organs.
- 1973:** US Supreme Court decision allows women to have abortions. (Should women have control over reproduction? What are the rights of the unborn?)
- 1976:** Karen Ann Quinlan's irreversible coma leads to the first legal case about life support and spurs right-to-die and hospice movements. (What is meaningful life? Who decides?)
- 1978:** Louise Brown, the first "in vitro baby"



is born. Discussions about "the manufacturing of babies in test-tubes".

- 1981:** Death is defined as "the irreversible cessation of cardio-respiratory function or the irreversible cessation of all the brain including the brain stem".
- 1982:** The Baby Doe case: where the parents of a Down-Syndrome baby decline surgery as part of neonatal care – a decision upheld by the courts. (Does anyone have the right to decide that a baby's life is not worth living?)
- 1982:** Barney Clark, the first person implanted with a mechanical heart, causing suffering. (Is extend-

ing life an over-ruling criteria?)

- 1987:** Case of a surrogate mother refusing to relinquish the baby borne for another couple where she obtains visiting rights. (What determines a parent?)
- 1990:** Human genome projects gets underway, mapping and sequencing the human genome. The first human gene-therapy clinical trial. (Future prospects: manipulations?)
- 1990:** Discussion and opposition to the introduction of genetically manipulated foods and crops.
- 1993:** Fertility researchers claimed to have successfully cloned human embryos. (Design babies?)
- 1994:** An Italian woman gives birth at 62. (Is it unnatural and wrong to help post-menopause women to bear children?)
- 1994:** The State of Oregon accepts assisted-suicide by popular vote.
- 1995:** Concern about the use of chemical and biological weapons.
- 1996:** Dolly the sheep is cloned. (Who has the right to create life?)
- 1998:** Scientists establish cultures of human embryonic stem cells that can grow into specialized cells. Controversies in regard to the moral significance of embryos.
- 1999:** HIV vaccine trials raise questions about the use of placebos in clinical trials conducted by wealthy nations.
- 1999:** Death of Jesse Gelsinger in gene therapy experiment raises further questions about protection of human subjects.
- 2000:** The complete draft of entire human genome raises questions regarding the future.
- 2002:** The Netherlands becomes the first nation to legalize euthanasia.
- 2005:** Terri Schiavo dies after a "right-to-die" case ruled by the Florida Supreme Court.

Main source: The Baltimore Sun



WHAT IS THE CHURCH'S TEACHING ROLE IN BIOETHICS?

When God created Adam and Eve, he placed them in a garden and blessed them. He told them, “Be fertile and multiply; fill the earth and subdue it. Have dominion over the fish of the sea, the birds of the air, and all living things that move on the earth” (Gen 1:28).

The Catholic Church has long understood this passage both as a reference to man's unique stewardship over nature and a justification for the pursuits of science.

The Church is not nor has it ever been antagonistic to scientific and medical progress per se. Indeed, more and more historians are analyzing the unique contribution that the Christian emphasis on human reason has made to the development of the arts and sciences in Western culture. Even the stereotypical blight on that record — the Galileo controversy — is now recognized to be much more complicated than what most of us learned in high school.

Though the Church is not against scientific and biomedical advancement, she nonetheless routinely challenges scientists and doctors with her teaching, which is itself

grounded in faith and reason. The reason the Church's teaching role is important in bioethics is that science is not morally neutral. This news may come as a surprise to many since science and medicine purport to be objective disciplines.

In his encyclical, *Saved in Hope*, Pope Benedict XVI recounts the history of the scientific movement, tracing it back to Francis Bacon and the seventeenth century. With the excitement of New World and a spate of scientific discoveries, a new era emerged. The basis of this new era was “the new correlation of experiment and method that enables man to arrive at an interpretation of nature in conformity with its laws and thus fully to achieve ‘the triumph of art over nature’” (no. 16). But like any other human endeavor, the presuppositions of science and medicine carry the moral baggage of their practitioners. For all the





progress and advancement we have achieved in the subsequent centuries, we have also seen our fair share of the destruction of human life in the name of that progress. No matter the promises offered, science cannot employ any means whatsoever to achieve its desired goals.

Pope Benedict, like Pope John Paul II before him, recognizes the incipient temptation of science to reduce the human person to yet another material object to be analyzed, experimented upon, and manipulated according to the empirical method. Science cannot offer us the meaning of life and it cannot reveal to us the dignity of the human person. Human reason is always confronted by its limitations when faced with these questions. In our zeal for scientific accomplishment and medical progress, we can be blind to this fact.

In the Catholic tradition, faith heals reason, purifies it, and reinforces it. There is no opposition between the two. Pope Benedict spoke eloquently of this in *God is Love*, his first encyclical. He wrote, "Faith by its specific nature is an encounter with the living God- an encounter opening up new horizons extending beyond the sphere of reason. But it is also a purifying force for reason itself. From God's standpoint, faith liberates reason from its blind spots and therefore helps it to be ever more fully itself" (no. 28).

This, then, is the role that Church teaching plays in bioethics. The teaching of the Church, grounded in the revelation of Jesus Christ, testifies to the dignity of the human person against any and all procedures that treat men, women, and children as mere means to human progress. When the Church addresses bioethical issues, she is guided by a few basic principles

First, man has a unique dignity above all other creatures on earth. As the Second Vatican Council taught, man is the only creature created by God "for its own sake" (*Pastoral Constitution on the Church in the Modern World*, no. 24). Man's unique status is the result of

his being created in the image and likeness of God (Gen. 1:27), on the one hand, and called to communion with him, on the other.

Second, God is the Lord and author of life. He alone gives the gift of life. Every person has the right to accept that gift. Every man, woman, and child has a fundamental right to life.

Finally, contrary to popular opinion, the human body is no mere shell or collection of cells and organs to use as we please. Neither is the human person reducible to the outward appearance of the body. Rather, Catholics believe that the human person is a holistic composite of body and soul. Both are intricate principles of the human being. What happens to either affects the person in some way — whether it be sin in the soul or genetic modification of the body. Try as we might, we are not indifferent to either.

The Church always works to remind men and women of their inherent dignity and moral responsibility as children of God. While applauding the advancement of science and medicine at the service of the human person, she does not remain silent when that dignity is forgotten. While she respects the authority scientists and doctors have in their own field, the Church will always warn against research that dismisses human dignity. As promising as stem cell therapies are, for example, we cannot tolerate those forms of research that destroy human life in its earliest stages to acquire those stem cells. It would be contrary to the dignity of the human person to do so. In *Saved in Hope*, the pope cautioned, "If technical progress is not matched by corresponding progress in man's ethical formation, in man's inner growth, then it is not progress at all, but a threat for man and the world" (no. 22). The Church's mission in bioethics is thus no different than her mission to the world, which is the spread the Gospel -the message of who we are and who we are called to be in Christ.

Fr. Thomas Petri O.P.

VOICES OF CRITICISM



Dr. Werner Arber, the head of the Pontifical Academy of Sciences and a Nobel Prize-winning genetic scientist, states that in some areas the Vatican's approach remains problematic. He works as an adviser to the Vatican on matters of scientific development and regularly provides recommendations on areas of overlap between science and faith.

Speaking to CNN, Arber said that rather than dealing head on with conflicts between science and the Bible, scientists like him often had to avoid them: "I don't propose certain topics which I consider taboo. Unless we are asked, we had better not mention them." In particular, Arber is uncomfortable with the Vatican's insistence that condoms aren't the right way to prevent the spread of HIV/AIDS, which he says is "unrealistic".

Jeremy Webb, editor-in-chief of *New Scientist* magazine, says the speed at which new developments are emerging in the biological sciences is increas-

ingly bringing about conflicts with the Vatican. In particular Webb sees this in relation to reproductive technologies -- such as in vitro fertilization (IVF), and egg and sperm donation -- all of which the church says are improper methods of procreation.

"The church is taking its viewpoint from 2,000-year-old teachings and trying to apply them to a modern world, which is delivering all sorts of moral dilemmas," he said to CNN.

Webb doubts there will be any significant change in the Vatican's fundamental attitude to contraception under Pope Francis and believes this will remain a sticking point between the biological sciences and the church.

"Catholics believe that anything that threatens the sanctity of life - including contraception - is wrong. That is a barrier and it will always be a barrier."

Werner Arber is optimistic that the Vatican will eventually catch up with the scientific evidence: "I have hope but - as with Galileo -- it will take a long time."

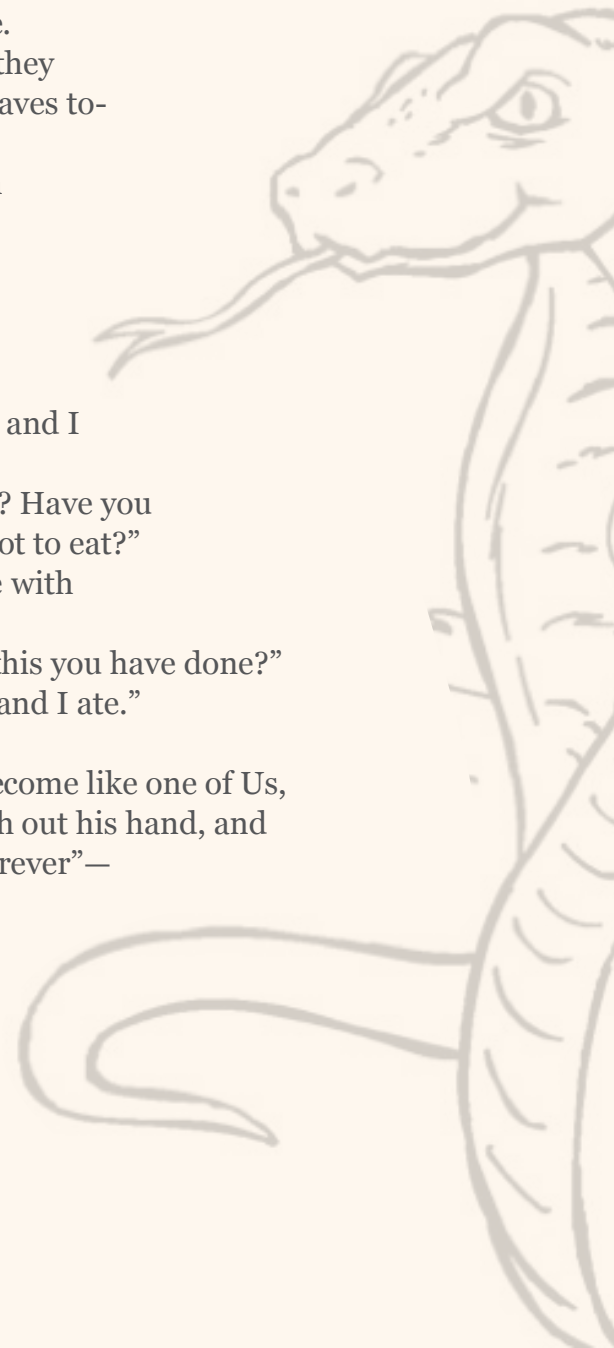
Source: CNN

WHAT THE BIBLE TELLS US

(GENESIS 3)



- 1 Now the serpent was more crafty than any beast of the field which the Lord God had made. And he said to the woman, “Indeed, has God said, ‘You shall not eat from any tree of the garden?’”
- 2 The woman said to the serpent, “From the fruit of the trees of the garden we may eat;
- 3 but from the fruit of the tree which is in the middle of the garden, God has said, ‘You shall not eat from it or touch it, or you will die.’”
- 4 The serpent said to the woman, “You surely will not die!
- 5 “For God knows that in the day you eat from it your eyes will be opened, and you will be like God, knowing good and evil.”
- 6 When the woman saw that the tree was good for food, and that it was a delight to the eyes, and that the tree was desirable to make one wise, she took from its fruit and ate; and she gave also to her husband with her, and he ate.
- 7 Then the eyes of both of them were opened, and they knew that they were naked; and they sewed fig leaves together and made themselves loin coverings.
- 8 They heard the sound of the Lord God walking in the garden in the cool of the day, and the man and his wife hid themselves from the presence of the Lord God among the trees of the garden.
- 9 Then the Lord God called to the man, and said to him, “Where are you?”
- 10 He said, “I heard the sound of You in the garden, and I was afraid because I was naked; so I hid myself.”
- 11 And He said, “Who told you that you were naked? Have you eaten from the tree of which I commanded you not to eat?”
- 12 The man said, “The woman whom You gave to be with me, she gave me from the tree, and I ate.”
- 13 Then the Lord God said to the woman, “What is this you have done?” And the woman said, “The serpent deceived me, and I ate.”
- 22 Then the Lord God said, “Behold, the man has become like one of Us, knowing good and evil; and now, he might stretch out his hand, and take also from the tree of life, and eat, and live forever” —
- 23 therefore the Lord God sent him out from the garden of Eden, to cultivate the ground from which he was taken.
- 24 So He drove the man out; and at the east of the garden of Eden He stationed the cherubim and the flaming sword which turned every direction to guard the way to the tree of life.



FREEDOM PUT TO THE TEST

- 396 *God created man in his image and established him in his friendship. A spiritual creature, man can live this friendship only in free submission to God. The prohibition against eating "of the tree of the knowledge of good and evil" spells this out: "for in the day that you eat of it, you shall die." The "tree of the knowledge of good and evil" symbolically evokes the insurmountable limits that man, being a creature, must freely recognize and respect with trust. Man is dependent on his Creator, and subject to the laws of creation and to the moral norms that govern the use of freedom.*
- 397 *Man, tempted by the devil, let his trust in his Creator die in his heart and, abusing his freedom, disobeyed God's command. This is what man's first sin consisted of. All subsequent sin would be disobedience toward God and lack of trust in his goodness.*
- 398 *In that sin man preferred himself to God and by that very act scorned him. He chose himself over and against God, against the requirements of his creaturely status and therefore against his own good. Created in a state of holiness, man was destined to be fully "divinized" by God in glory. Seduced by the devil, he wanted to "be like God", but "without God, before God, and not in accordance with God".*
- 399 *Scripture portrays the tragic consequences of this first disobedience. Adam and Eve immediately lose the grace of original holiness. They become afraid of the God of whom they have conceived a distorted image - that of a God jealous of his prerogatives.*
- 400 *The harmony in which they had found themselves, thanks to original justice, is now destroyed: the control of the soul's spiritual faculties over the body is shattered; the union of man and woman becomes subject to tensions, their relations henceforth marked by lust and domination. Harmony with creation is broken: visible creation has become alien and hostile to man. Because of man, creation is now subject "to its bondage to decay". Finally, the consequence explicitly foretold for this disobedience will come true: man will "return to the ground", for out of it he was taken. Death makes its entrance into human history.*

From the Catechism of the Catholic Church

FREEDOM PUT TO THE TEST

SPERM DONATION

Sperm donation is the donation by a man of his sperm principally for the purpose of inseminating a woman who is not his sexual partner. Sperm may be donated privately and directly to the intended recipient, or through a sperm bank or fertility clinic. The primary recipients of donor sperm are heterosexual couples suffering from male infertility, lesbian couples and single women.

While a sperm donor is regarded as the natural or biological father of every child produced as a result of his donation, he is generally not intended to be the legal or de jure father.

Several jurisdictions, e.g. Sweden, Norway, the Netherlands, Britain, Switzerland, Australia and New Zealand, and others, only allow non-anonymous sperm donation, generally based on the principle that the child has a right to knowledge of his/her biological origins.

Catholicism officially opposes both the donation of sperm and the use of donor sperm on the basis that it compromises the sexual unity of the marital relationship and the idea "that the procreation of a human person be brought about as the fruit of the conjugal act specific to the love between spouses."

Source:Wikipedia

Egg donation and IVF

Egg donation is the process by which a woman donates eggs for purposes of assisted reproduction or biomedical research. For assisted reproduction purposes, egg donation typically involves in vitro fertilization technology, with the eggs being fertilized in the lab-

oratory; more rarely, unfertilized eggs may be frozen and stored for later use. Egg donation is a third party involvement as part of assisted reproductive technology (ART).

Prior to this, thousands of infertile women, single men and gay male couples had adoption as the only path to parenthood.

This scientific breakthrough changed the outlook for those who were unable to have children due to female infertility and for women who are at high risk for passing on genetic disorders.

In popular terms this could be called "egg adoption", although in some cases the psychological adoption of the growing baby does not happen.

In vitro fertilisation (IVF) is a process by which an egg is fertilised by sperm outside the body: in vitro ("in glass"). The process involves monitoring and stimulating a woman's ovulatory process, removing ovum or ova (egg or



eggs) from the woman's ovaries and letting sperm fertilise them in a liquid in a laboratory. The fertilised egg (zygote) is cultured for 2–6 days in a growth medium and is then implanted in the same or another woman's uterus, with the intention of establishing a successful pregnancy.

Today, egg donation is practically a household word. But not so long ago, it was a mysterious procedure for infertility that produced what were then known as "test-tube babies." Louise Brown, born in England in 1978, was the first such baby to be conceived outside her mother's womb.

Unlike the simpler process of artificial insemination- in which sperm is placed in the uterus and conception happens otherwise normally - IVF involves combining eggs and sperm outside the body in a laboratory. Once an embryo or embryos form, they are then placed in the uterus. IVF is a complex and expensive procedure; only about 5% of couples with infertility seek it out.

IVF may be totally illegal (e.g., Italy, Germany, Austria); legal only if anonymous and gratuitous (e.g., France); legal only if anonymous, but egg donors may be compensated (e.g., Spain, Czech Republic, Greece); legal only if non-anonymous, but egg donors may be compensated (e.g., the UK) According to The European Convention of Human Rights the anonymity of an egg donor violates the human right of knowing one's origin.

Embryo donation is, as its name implies, the donation of embryos remaining after one couple's IVF treatments have been completed, to another individual or couple. The embryos created for one couple, using an egg donor, are often made available for donation

to another couple if the first couple chooses not to use them.

Some Christian leaders indicate that IVF is acceptable (but they should ensure that no fertilized embryos are discarded in the process). Many Christian couples who cannot have children thus can go for IVF, with both the husband's sperm and the wife's egg according to the teaching of their church. However, the question gets trickier with donor eggs.

Catholic theologians are concerned about all in vitro fertility therapies because they disrupt the natural act of conceiving a child where both egg and sperm donations are seen to "compromise the marital bond and family integrity". They encourage infertile couples to consider adoption instead.

Source: Wikipedia a.o.

A WOMAN'S FEELINGS CONSIDERING EGG DONATION (excerpts)

....

What was my problem, then? Was it ego? There were particular family attributes I felt I wanted to pass on in my genes, inherited assets that were evident in my nieces that I didn't want a child of mine to miss out on. I also wondered whether I would be able to bond properly with a child who lacked any family resemblance. Would I recognise him or her as mine?

I couldn't help remembering the countless times I had sized up an infant and said, "He's got your eyes!" or, "Doesn't she look like her dad?" Using another woman's eggs would rule out the possibility of spotting my brother's dimples

in my child, or my granny's way with a sewing machine. I pictured friends and relatives walking on eggshells when it came to discussing familial resemblance, or putting their foot in it, or just trying to be kind. "It's funny, she looks just like you, even though she's, you know, not, er..."

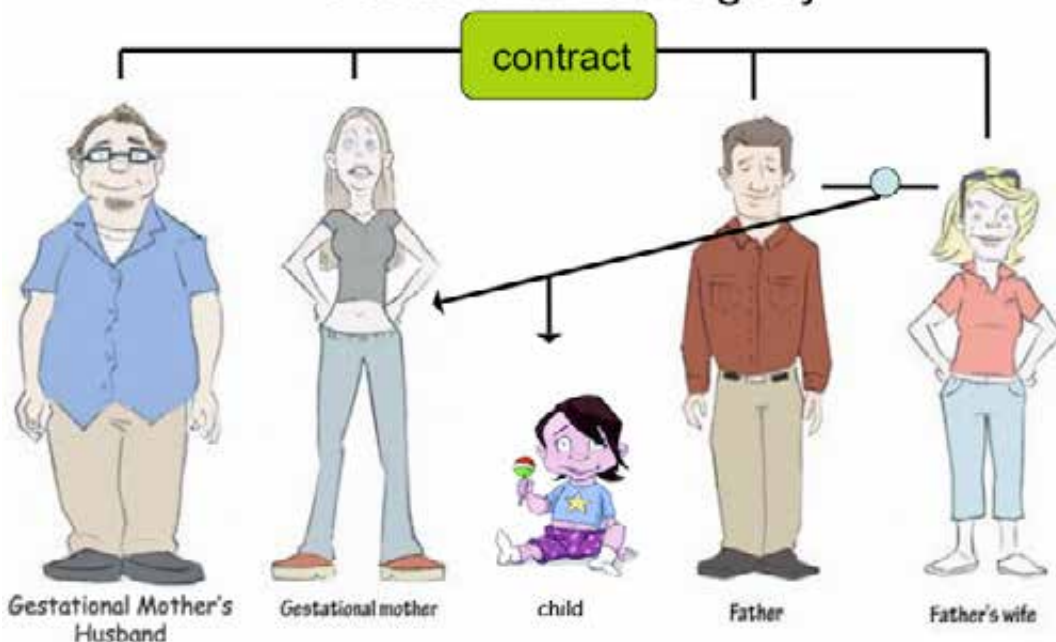
Genealogy was also an element: I've always relished hearing about what my grandparents did in the war and looking at grainy photographs of my great-grandparents. How would donor egg kids feel about their antecedents if they weren't blood-related to them? "Do we need to tell them?" ...We decided it would be wrong to keep it a secret. How could we teach them to be honest if we were deceiving them?

Of course, they would always be able to trace their forebears on Richard's side, but that wouldn't involve me and all my wonderful tales... I don't know why I was being so obtuse. None of these concerns has ever troubled my sister and her gorgeous adopted sons,

as far as I know. What's more, the parent I most loved and from whom I received the most care and affection in my life was my now deceased stepmother, with whom I shared not a chromosome, gene or blood cell. Looks were a concern. After all, it's been proved that life is easier if you're attractive, and I wanted the best for my child. But whereas – rather sickeningly – in America you can choose your donor by watching a video of her, and I believe you pay extra for prettier and better-educated women's eggs, in Europe you're not supposed to care about such things. Current health of the donor and family medical history are the important factors – and rightly so.

A close friend of Richard's volunteered her eggs. It was an incredibly kind and generous offer, but I much preferred the idea of an anonymous donor. I sensed I would feel uncomfortable having a friend around a child produced from her eggs. There just might be an ownership issue there, if only in my imagination.

Gestational Surrogacy



...
I'd read interviews with grown-up test tube babies who felt upset or depressed by the thought of the clinical circumstances surrounding their conception. But could I really take such sensitivities into account? After all, I have never in my life dwelt on the circumstances of my own conception ...
On a monitor I watched two magnified embryos gently drift their way

inside me. Two weeks later, Richard and I rejoiced cautiously at my positive pregnancy test. Four weeks after that, I had a scan in London and listened to the thump-thump-thump of two foetal heartbeats...

We just can't wait to meet our babies, whoever they are.

Briony Walker

(14 May 2011 The Guardian)

CATHY'S STORY (excerpts)

When I first thought about donating my eggs I talked to the doctors and researched on the internet but the information about the risks are drowned out by all the information provided by people and companies searching for young eggs...

I was devastated by my loss of fertility and new hormone problems. I was angry about the way the fertility clinic treated me when I needed follow up after the egg donation. The doctors made me believe that my side effects would eventually clear up and my body would go back to normal. ...that has not happened. My body has not gone back to normal. I still have to take medications to regulate my hormones. I will never be back to normal and so I feel a need to warn other young women out there that donating your eggs is not as safe as everyone will make you believe. There are risks and very serious ones!..

I grew up in foster care and worked hard with the hope that a family would want me.

I was never paid for my eggs. I gave my eggs away. A few years ago, I gave my eggs to good friends with the naive belief that this was a way for me to be part of a family—and I would even have a genetic connection! I was promised that I would always be part of the family and the child's life. I wanted to give my friends what I never had—a family. I thought, "When would I ever have a chance to make such a huge difference in someone's life again?" And I would be part of a family

too. Knowing what it's like to yearn for family, I went through with the egg donation for my friends. I had to take some genetic tests for diseases, health tests, and a counseling session over the phone. The counseling session was about my life history and how the egg donation might affect my friends. It was never about my psychological needs. I produced an unreal 47 eggs. At first I felt pride in that. Now that I know better, I am angry that the doctors risked my health and allowed twice the normal amount of eggs normally produced ...
Immediately after the retrieval, I had a lot of bleeding and discomfort. I became severely depressed to the point where I needed antidepressants but my mental health continued to decline. My periods stopped.

I will be on drugs to control my hormones for the rest of my life. I still go months without a period. My mental health continues to be an issue and is very much linked to my hormones. My ovaries have remained enlarged and I will most likely never be able to conceive naturally, if at all...

My friends promised me I could have the remaining embryos, but they have since changed their minds. They've changed their



minds about a lot of things.

My friends have decided that I am no longer part of their family. She cannot handle that her son looks exactly like me. She is devastated that her son has no genetic link to her. She wishes he had come out looking like her husband because I remind her that he's not hers. I'm not sure what she expected when she took my DNA. I'm no longer part of my "nephew's" life after loving him for over two years; I have to stalk the father's blog to watch him grow up. I would have never given them my eggs had I thought I would not be a part of the child's life.

My devastation and drastic mood swings became too much for me and I attempted to end my life. I donated my eggs out of a desire to mend the broken hearts of people

that I love and my own. What I got in return was a hormonal disorder, major depression, infertility, and another family abandoning me for reasons I do not understand. I wish I could go back in time and spare my body, fertility, mind, and my heart.

Egg donation is NOT harmless like I was led to believe. It has seriously affected every part of my life. I often cry about the loss of my friends, my family, the little person with half my DNA and my ability to have my own genetic children someday. If you're thinking about donating your eggs for ANY reason-- DON'T. It's not worth it.

From a Documentary

Film by The Center for

Bioethics and Culture

WHAT IS SURROGACY?

Surrogacy is when another woman carries and gives birth to a baby for the couple who want to have a child.

There are two kinds of surrogate mothers:

A. Traditional surrogates:

A traditional surrogate is a woman who is artificially inseminated with the father's sperm. She then carries the baby and delivers it for the parents to raise. A traditional surrogate is the baby's biological mother because it was her egg that was fertilized by the father's sperm. Donor sperm can also be used for a traditional surrogacy. Here the surrogate mother's egg is fertilized with the sperm of a donor - not the male part of the commissioning couple.

B. Gestational surrogate:

In Vitro Fertilization (IVF) now makes it possible to harvest eggs from the mother, fertilize them with sperm from

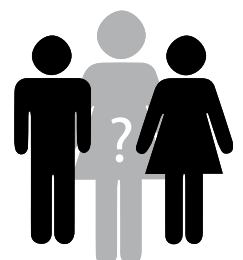
the father, and place the embryo into the uterus of a gestational surrogate. The surrogate then carries the baby until birth. A gestational surrogate has no genetic ties to the child because it was not her egg that was used. A gestational surrogate is called the "birth mother." The biological mother, though, is still the woman whose egg was fertilized.

An embryo can also be created using donor eggs and sperm.

Who Uses Surrogates?

A woman might decide to use a surrogate for several reasons: She may have tried to get pregnant with a variety of assisted-reproduction techniques, have medical problems with her uterus or a medically risky condition.

Surrogates have also made parenthood an option for people who might not be able to adopt a child.



Reasons could include: their age, marital status or sexual orientation. For instance, when gay men use a traditional surrogate, one of them uses his sperm to fertilize the surrogate's egg through artificial insemination. The surrogate then carries the baby and gives birth. A gay couple might also choose an egg donor, fertilize that donated egg, and have the resulting embryo implanted in a gestational surrogate to carry until birth.

Monetary compensation may or may not be involved in these arrangements.

If the surrogate receives compensation beyond reimbursement of medical and other reasonable expenses, the arrangement is considered commercial surrogacy; otherwise, it is referred to as altruistic. Egg donation just as surrogacy is prohibited in Germany, Austria and Switzerland and other countries. Surrogacy is allowed in the UK, Belgium, the Netherlands, Greece, Russia and Ukraine, Israel, Australia and Canada and in 18 states of the USA. In India surrogacy has already become a Global Business!

Source: Web MD

A large, artistic photograph of a hand holding a glowing, multi-colored orb. The hand is in the foreground, and the orb is in the center, emitting a soft, ethereal light. The background is a gradient of colors, from deep red on the left to bright blue on the right, with yellow and green in the middle. The overall mood is warm and hopeful.

A SURROGATE MOTHER WRITES:

“We’re not rich people ... but it’s one way our family can give back in a really big way.” I have been a surrogate mother three times (twins in February 2007 and a little boy in June 2008), and I’m about to give birth this month to my fourth surrogate baby. The best part is knowing you did this for the right reasons when you deliver the baby and the parents finally see him or her.

But there are a lot of sacrifices a surrogate makes. There are hormone shots that my husband had to help me take for three months, prior to the transfer and then almost through the first trimester. With varying state laws on surrogacy, you may have to stay in state. My husband had to turn down a promotion in another state, and I missed Christmas with my in-laws during my

3rd trimester with twins because my doctor said I couldn't travel. I'm one of the fortunate people that is "good" at being a surrogate mother. Every embryo that doctors have transferred has ended with a full-term healthy baby. That's rare. After my first time as a surrogate, I waited three years and worked on my surrogacy website and wanted to do it one more time. Addicting is not the right word, but the ability to help someone else is a very good feeling.

As for handing the baby off I knew instinctually that I'm not an attached type of person. I always viewed surrogacy as a long babysitting project. I'm going to give birth any day now

and I'm excited that the parents will be there. It's not sad for me at all. I have no regrets whatsoever – I'm just glad I was able to participate. We're not rich people. We'll never donate a wing of a hospital, but it's one way our family can give back to our world in a really big way. Without our assistance, there would be four less children in the world. We are showing our own children how to be generous and how to sacrifice for others.

Rayven Perkins,
32, Austin, Texas, married, mother
to a girl(10) and a boy (11)

INTERNATIONAL TRYING TO TAME THE WILD WEST OF SURROGACY IN INDIA BY RAKSHA KUMAR

The Surrogacy India clinic in Mumbai has rented a room in a slum for surrogate mothers to carry the fetuses for the clinic's clients. Divya is 28, in her seventh month of pregnancy and a surrogate for an Australian couple in their 40s. This is not the first baby Divya has carried that is not her own — there was another in 2010, for an Indian couple. She is one of the millions of surrogates who help to generate 24.8 billion rupees in revenue each year and, along with roughly 3,000 clinics that provide in vitro fertilization, have turned India into the surrogacy capital of the world. Because surrogacy is legal but not regulated, surrogates like Divya are subject to exploitation by middlemen, clinics and would-be parents, say women's health advocates.

Surrogacy, the practice of carrying a baby for someone, can be gestational, in which the surrogate is implanted with a fertilized egg that has no genetic relationship with her, or traditional, in which the surrogate is artificially inseminated and is genetically related to the baby. India has no laws on commercial surrogacy — just loose guidelines which experts call toothless and woefully inadequate.

Without a law, there are no provisions to address everything that could go wrong. In 2008, for instance, a Japanese couple that had arranged for an Indian surrogate to carry their baby divorced before the baby was born. Though the father wanted the baby, Indian law doesn't permit single men to adopt, so Baby Manji remained in a Jaipur hospital for two years until cus-



tody could be resolved. Last October, an Australian couple abandoned one of their twin babies born to a surrogate in Delhi because they already had a child of the same sex. And in Mumbai, would-be parents Ravi and Divya Kapoor claim that the total cost of the surrogate pregnancy they commissioned turned out to be more than two and a half times the 10,00,000 rupees (about \$16,100) that was agreed on.

The easy availability of surrogates, the clean medical facilities, the presence of a large English-speaking population and government emphasis on medical tourism have drawn thousands of foreign couples to India ever since surrogacy was legalized in 2002. Today, leading clinics in the country oversee anywhere from 100 to 300 surrogate pregnancies every year.

“In this business, the baby is the product. The surrogate is the means of production. Even those who care for the surrogate do so until the product is delivered,” says Ranjana Kumari, director of the nonprofit Centre for Social Research, which works on women’s issues. “The surrogate is waste material for them after the delivery.”

“I talk to the child all the time,” Divya says in Hindi, touching her bulging belly in the protective gesture of pregnant women everywhere. “My mother used to say he understands you and the pain you go through. Therefore, he will bond better with you when he grows older.”

A second later, she bites her lip. “I always forget he will not be with me in a few months’ time,” she says with a nervous laugh.

Nine months of pregnancy, the hard work of labor and the physical and mental toll that carrying a baby takes on a body aren’t reflected in the compensation she receives from the clinic where she is registered, Divya says. She is promised 3,000 rupees as “food and well-being” expenses every month by the clinic she works with in Delhi. But the lion’s share is taken by middlemen who connect women like Divya with the clinics. And she is left with barely 1,300 rupees, not even enough to pay her 8-year-old son’s school fees.

Unfortunately for Divya, she is working with a lesser-known clinic in Delhi and doesn’t get any benefits. She lives in a 12-by-12-foot shanty made of wood,

ragas and plastic sheets; till the sixth month of her pregnancy, she cleaned the house and cooked for her family of four. Only recently did she stop her daily chores and moved to a home provided by the clinic, where she is receiving medical care for the last months of her pregnancy. “All hell will break loose at the clinic if I do not deliver a healthy baby,” she says. “And, unlike the surrogates in fancy clinics, I get paid only 200,000 rupees after delivery. Only half of what they earn.”

Surrogacy has been commercially available in the West since the late 1970s, when the first “test-tube baby” was born in England. Many countries, such as England and Australia, have banned commercial surrogacy for ethical, religious and medical reasons, as have some states in the United States. Those that haven't banned the practice ensure that the industry is stringently regulated. Except for India.

Here, commercial surrogacy has been permitted for more than a decade, but without government regulation, surrogates have to accept the terms that clinics give them. Divya, like many surrogate moms in India, is illiterate. Desperate for the funds, she agreed to the contract by thumbprint, without knowing what the “stuff written in English” meant. A 2013 study conducted by the nonprofit Centre for Social Research found that 88 percent of surrogate mothers interviewed in Delhi and 76 percent in Mumbai did not know the terms of their contract. In fact, 92 percent of those in Delhi did not even have a copy of it.

Today, surrogacy contracts typically exclude the surrogate herself and are usually between the clinic and the commissioning parents, who agree to accept all the consequences of their decision, says Gita Aravamudan, author of the 2014 book “Baby Makers:

The Story of Indian Surrogacy.”

Despite all the hurdles, many women choose to be surrogates because the pay makes a difference to their families..”

About 90 miles north of Delhi is Jind, a rural district in the state of Haryana infamous for its skewed sex ratio in the state of Haryana. Divya and her husband moved from Jind to Delhi a decade ago in search of more-lucrative jobs. Two years after they settled into their shanty in Gadhi they met Rahman bhai. A smooth talker, Rahman bhai explained the technicalities of surrogacy. A major part of the middleman's job is to convince women that what they are doing is not immoral. These middlemen — not formally affiliated with clinics, which usually pay them clandestinely — are largely invisible on paper.

In 2009, Divya's father-in-law contracted tuberculosis and her husband injured his hand while working as a construction laborer. Divya, who till that point had been a housewife, felt she needed to step up and help the family financially. After several rounds of egg donation at the same Delhi clinic she is working with now, she carried her first baby as a surrogate mom in 2010. After the child was born, she was paid 35,000 rupees for her services. She was later told that Rahman bhai had made almost as much just by playing middleman.

Divya is due to deliver the baby she is carrying in March. This is probably the last time she will be a surrogate, as most clinics want surrogates in their mid-20s. But her sister Durga is 23 and a potential candidate.

“The lawmakers have failed me,” Divya says, “but I hope they frame better laws by the time Durga gets ready to enter the business.”

THE CATHOLIC CHURCH AND SURROGACY

The Catholic Church is pro-life, and this not only means “not killing” and “actively supporting” life, but it also means being open to new life as well. The Church therefore obviously wants to support the desire of married couples to be parents, but to do so in a way that is in line with God’s intention for how flourishing children come into the world. Thus all technologies which are designed to aid the mechanisms God has given us for procreation are perfectly acceptable, according to the Church. Women and men can take drugs or have surgeries to improve their fertility or their sexual capabilities, for instance.

However, the Church wants to push back against our culture’s understanding that children can be created with technology and distributed via a market. Children are to come as a gift from God via a sexual relationship

— instead of being procured as a product or thing. Any reproductive procedure that involves something other than aiding sex and pregnancy within the context of a married couple permanently committed to being the parents of this child together is something the Church insists misses the mark. This includes everything from creating a child in a laboratory to the use of another person as a surrogate to carry the child through pregnancy. The fact that some of us will not be able to be biological parents is a painful one, but the Church claims this is one of the hard truths that we must endure if we believe that children are gifts with their own inherent dignity — rather than things we have the right to purchase on the open market.

Charles C. Camosy, PhD

PRENATAL CARE, EMBRYO SELECTION AND GENETIC TESTING

Obstetric ultrasonography is the application of medical ultrasonography to obstetrics, in which sonography is used to visualize the embryo or fetus in its mother's uterus (womb). The procedure is a standard part of prenatal care, as it yields a variety of information regarding the health of the mother and of the fetus, the progress of the pregnancy, and further information on the baby.

The sex of the fetus may be discerned by ultrasound as early as 11 weeks gestation.

Abnormality screening

In some countries, routine pregnancy sonographic scans are performed to detect developmental defects before birth abnormalities. Some abnormalities detected by ultrasound

can be addressed by medical treatment in utero or by perinatal care, though indications of other abnormalities can lead to a decision regarding abortion.

Perhaps the most common screening is the Nuchal Scan to determine the Down syndrome. 91% of the fetuses affected exhibit this defect; 5% of fetuses flagged by the test do not have Down syndrome.

Ultrasound may also detect fetal organ anomaly. Usually scans for this type of detection are done around 18 to 23 weeks of gestational age.

PGD (also called PID)

Pre-implantation genetic diagnosis (PGD) is a screening test used to determine if genetic



or chromosomal disorders are present in embryos produced through in vitro fertilization (IVF). Studies have shown that as many as 50% of embryos are chromosomally abnormal. Pre-implantation genetic diagnosis screens embryos before they are transferred to the uterus. Embryos unaffected by the genetic or chromosomal disorder can be selected for transfer to the uterus. For couples undergoing IVF, PGD may be recommended when:

- One or both partners has a history of heritable genetic disorders
- One or both partners is a carrier of a chromosomal abnormality
- The mother is of advanced maternal age
- The mother has a history of recurrent miscarriages

Source: Penn Medicine

NGS

Connor, a healthy baby boy, has made history. He is the first child to be born after his parents had the entire ge-

nomes of a batch of their IVF embryos screened for abnormalities, with the intention of picking the healthiest for implantation.

Although the researchers stopped short of actually sequencing the boy's genome, the advance is proof that this could be done – potentially ushering in an era of designer babies.

IVF accounts for between 1 and 5 per cent of all births in developed countries, but it is very inefficient. An estimated 80 per cent of embryos either don't implant or miscarry, while only a third of IVF cycles result in a successful pregnancy, largely due to abnormalities in the number of chromosomes an embryo possesses.

"If you take a woman in her early 30s, around a quarter of her embryos will be abnormal. For a woman in her early 40s, it's around three-quarters," says Dagan Wells at the University of Oxford, who pioneered the new technique. The problem is that many abnormal embryos look normal under a

microscope. "We need better ways of working out which embryo is the one that we should implant," says Wells. To do this, he first took cells from seven 5-day-old embryos and extracted their DNA. He then used a technique called next-generation sequencing (NGS) to assess the number of chromosomes in each cell. This involves breaking the DNA into fragments that

a computer then reads and predicts where on the chromosome each fragment came from. The sequence of an entire genome can be read in this way – although Wells's team didn't do this. They were merely interested in the proportion of DNA coming from each chromosome.

Source: New Scientist (2013)

GENETIC TESTING (EXCERPT OF INTRODUCTION TO AN ESSAY)

With Angelina Jolie's electing to have a double mastectomy because she carried the BRCA Gene, and her mother and aunt died at a very early age of the disease, the issue of genetic testing is in the forefront again.

"After nine months of worrying and diligent pre-natal care, the day to meet your unborn child is here. Labor is long and for hours you lie in the birthing suite riding out contraction after contraction. The moment finally arrives and you discover you have a son; ten fingers, ten toes and seemingly healthy lungs by the cry that you hear. He is then quickly taken over to the nurse's station and a drop of blood from his heel is placed into a machine that in seconds will decode his entire genome. Soon your son's future will be written in stone; he has a life expectancy of 30.2 years and has a 99% chance of dying from heart failure. In that instance, your son has been labeled as an invalid and he is now doomed to exist within a lower class of society, one that will prohibit him from pursuing his dreams.

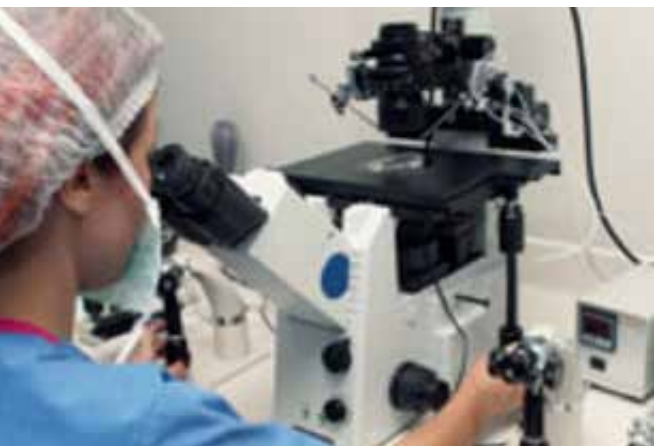
Society has discriminated against your new baby boy based solely upon his DNA. A new form of eugenics is born".

This was the opening scene of the 1997 science-fiction movie called "Gattaca." Besides pushing the bounds of human imagination, science fiction can serve as a warning about a future caused by the abuses of humankind. The opening birth scene in this movie is quickly becoming a potential reality. Now, a person's entire genome can be decoded and in an instant, a person knows whether he or she will be susceptible to Parkinson's disease, Alzheimer's disease, cancer, or other life threatening conditions. Proponents of genetic sequencing believe that this is the holy grail of medical care and tout phrases like "personalized medical care" and "significantly reduced costs of healthcare." There is a rapid movement towards this goal through the proposed expansion of newborn screening for eighty-four conditions, most of which are not understood or have no known treatment.

Michele Stopera Freyhaut

EMBRYO MITOCHONDRIAL MODIFICATION - A STEP TOO FAR?

Parliament in the United Kingdom has only recently (February) passed new legislation to allow, under licence, the creation of IVF embryos with genetic material derived from three individuals, for the purpose of overcoming the problem of inherited mitochondrial disease. It is the first country in the world to allow such genetic manipulation, leading to some descriptions in the press of "three-parent babies".



To understand the science involved it is first necessary to know that the DNA an individual receives from his/her parents consists of two types. Firstly, the Nuclear DNA - this is contained within the 46 chromosomes within the nucleus of each cell, (23 chromosomes from each parent). This nuclear DNA determines individual characteristics eg hair colour, height,etc. Secondly, there are small amounts (less than 0.1%) of DNA contained within small structures called mitochondria within the cytoplasm of each cell. As the cytoplasm of an embryo is derived from the cytoplasm of the maternal ovum, all the inherited mitochondrial DNA comes from the mother. This DNA, un-

like nuclear DNA, does not determine personal characteristics, but does control how the mitochondria function. Mitochondria are responsible how food and oxygen is used and for the energy needs of the cell, they have been compared to mini-power stations enabling each cell to work properly. Where this mitochondrial DNA is defective babies are born who die early from poorly functioning heart, muscle and other organ failure. Because the defective mitochondrial DNA is present in all the maternal eggs, all children born from affected women will be affected to a greater or lesser extent.

The technological advances that are the subject of this legislation are a result of research which has developed two different methodologies for replacing defective mitochondria with healthy ones. It is important to understand both techniques as they have different ethical implications. The first, called Pronuclear Transfer, is involves the creation of two fertilised eggs, one from the affected mother and one from another (healthy) woman. The nucleus from the health egg is removed and the nucleus from the affected egg is placed into the healthy cytoplasm. This new egg is then implanted via IVF into the affected mother. This method obviously involves the destruction of one healthy fertilised egg to produce another healthy baby. There is a second technique proposed, called Maternal Spindle Transfer. This involves transferring the nucleus of an affected egg, to the cytoplasm of a healthy egg prior to fertilisation. This has less ethical impli-

cations as there is no destruction of a fertilised egg, but it still involves IVF and does require egg donation from a healthy individual.

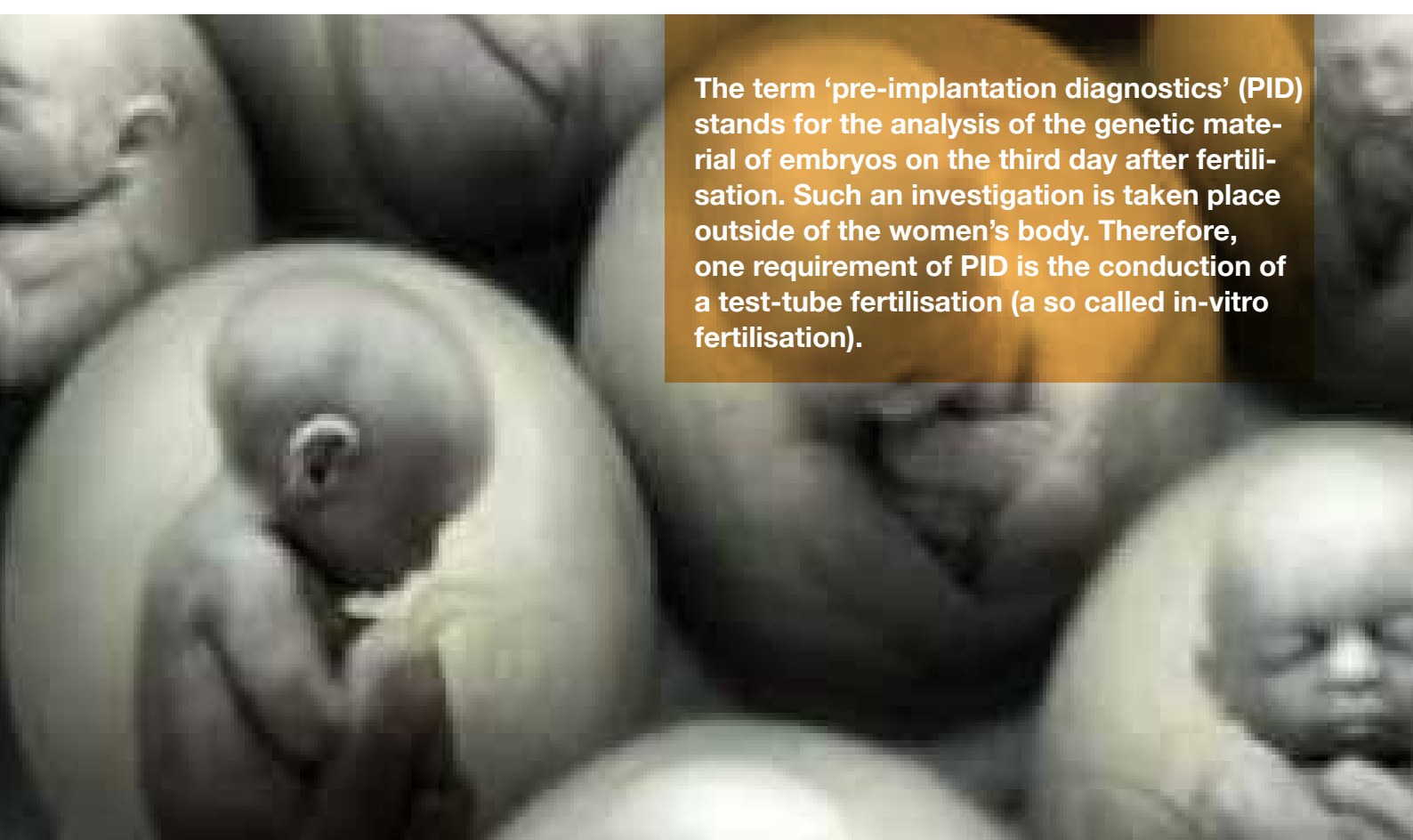
The ethical debate around this change in law does not just involve the fate of individual fertilised eggs, but wider issues about the responsibilities involved in changing the genetic inheritance of future descendant of those individuals born from this technique, all of who will carry the new mitochondrial DNA. Changing the germ-line (the genetic inheritance of future generations) is a threshold in scientific progress over which many are reluctant to step, and which European legislation opposes. (European Directive on Clinical trials) 2001/20/EC: " no gene therapy trials may be carried out which results in

modifications to the subjects germ-line"). The UK parliament have got around this by agreeing to treatments under licence without clinical trials. (A member of the NBCW bioethics committee has likened it to splitting the atom, once done, science cannot go back.)

The change in the law came after a period of public consultation during which it was clear that there was much public significant support, but many concerns were raised by individuals and churches. The National Board of Catholic Women sent its own comments which are available to those interested. Further information and analysis can be obtained from the Anscombe Centre for Bioethics website www.bioethics.org

Dr. Mary McHugh

THE MAIN ARGUMENTS FOR AND AGAINST PRE-IMPLANTATION DIAGNOSTICS By Dr. Regula Ott MD

A grayscale, artistic photograph of several embryos in petri dishes, arranged in a circular pattern. The focus is soft, creating a sense of depth and highlighting the delicate nature of the subjects.

The term 'pre-implantation diagnostics' (PID) stands for the analysis of the genetic material of embryos on the third day after fertilisation. Such an investigation is taken place outside of the women's body. Therefore, one requirement of PID is the conduction of a test-tube fertilisation (a so called in-vitro fertilisation).

Such a requirement is not needed in the case of pre-natal diagnostics (PND), where the health state of the embryo or foetus is tested while located inside the woman's body. Furthermore, PND is taken place at a later stage than PID – mostly between week 10 and 18 of the pregnancy.

At the moment when PID is conducted, therefore three days after fertilisation, the embryo consists of 6 to 10 cells and has more or less the size of a pencil dot. With the help of PID one can bring into experience, if the embryo bears the specific gene of a heritable illness, which is entailed on a single gene. Such so called monogenetic illnesses are very seldom, because the majority of illnesses are influenced by the interaction of a wide number of genes as well as environmental factors. One of the most common monogenetic illnesses in Europe is cystic fibrosis with a probability rate of 1:2'500. This illness leads among others to serious and chronic respiratory ailments and to a decreased life expectancy. Other inherited illnesses based on only one gene are e.g. Huntington's chorea or myotubular myopathy. Huntington's chorea breaks out in the fourth or fifth decade of a person, leading to the degeneration of specific nerve cells and in between 5 to 20 years to death. The defect gene in myotubular myopathy leads in boys to the absence of the maturing of muscle cells, which is fatal within the first weeks after birth. If a couple has one of these severe illnesses in their families, an embryo not affected with the illness can be selected with the help of PID.

Another application of PID is the so called chromosome screening.

Thereby it will be tested, if the chromosomes are regularly present in a twofold version or if three version of a chromosome (= trisomy) or only one version (= monosomy) is occurring. In the majority of the cases of trisomies or monosomies, the embryo dies already during pregnancy. About 50% of all miscarriages are based on a too high or too low number of chromosomes of the embryo. But a chromosome screening can also reveal which sex chromosomes the investigated embryo has. Thereby one knows in most of the cases which gender the embryo will have.

An often by law forbidden application of PID is the selection of embryos according to the tissue type. Thereby, stem cells of the umbilical cord are collected shortly after birth for donating to an older sibling with e.g. leukaemia. By chance, meaning without PID followed by selection, the probability rate of a sibling with a suitable tissue type for a donation would be 25%. Non-related person are only very seldom qualified as donors. Used terms in the media for this application of PID like savour baby or designer baby are critical reflected in literature, because they suggest either a duty of first aid or a form of human breeding.

Arguments for or against the application of PID are currently intensely discussed in various countries, because possible revisions of statues to allow PID are lined up or will be in short applied. I will here present briefly the main arguments of both sides. Thereby, I will neither focus on the sex determination nor on the selection based on the tissue type, because both of these applications are more controversial then the detection of

illnesses or the chromosome screening.

The main argument of the party against any application possibilities of PID refers to the worthiness of protection of the embryo. According to their opinion, such a worthiness of protection is absolute, starting from conception and can therefore not be weighed e.g. up against the life situation of the woman or the couple. Therefore, PID for the selection of an embryo cannot be supported because other embryos that will not be implanted will be rejected.

Representatives of the party who want to allow PID under certain determinations would also in most cases agree to a worthiness of protection of the embryo. But in their eyes, the worthiness of protection can be weighed up against certain aspects. Therefore the suffering of the couple can be weighed higher than the worthiness of protection of the embryo, if the suffering is unbearable for these persons. According to the opinion of these representatives, the allowance of PID will strengthen the autonomy of the woman or the couple, because she/they can decide for herself respectively for themselves, what an unbearable suffering means to her/ them. Families, who are affected with such a heritable illness, know the illness often very well and can estimate rather well what a life with a child bearing the illness will mean.

After all, the representatives of the party who want to allow PID will also ascribe an absolute worthiness of protection at the latest to a new-born. Therefore they assume an increase of a worthiness of protection during the development of the embryo, which

is the base for a further main argument of them. They assume that PID is morally less reprehensible compared to PND. This is based on the fact, that the selection of one embryo and the related rejection of the other embryos are taken place at an earlier stage than a PND with the possible consequence of an abortion.

There exist two different positions inside the party of people who want to allow PID: The position that wants to allow it only for the detection of a heritable illness if it occurs in the family and the position that wants to allow additionally the chromosome screening to all women who undertake a test-tube fertilisation. Some of the main reasons of the persons who want to limit the application of PID to women with monogenetic illnesses in their families are (1) the fear of discrimination of people with a disability in the society, (2) the pressure on women for giving birth to a healthy child and related to that a pressure of justification if PID or PND have not been conducted, (3) the fear of an extension of the characteristics according to which the selection will take place, and/or (4) missing frame conditions to prevent these concerns to come into place.

Represents of catholic association and institutions can be found on both sides concerning the debate around PID. In summary it can be said that the chosen position depends mostly whether the particular represents assume an absolute worthiness of protection beginning with the fertilisation of the embryo or considering a weighting up against an unbearable suffering of the women or the couple as ethical justifiable.

WHAT ARE STEM CELLS?

Stem cells are mother cells that have the potential to become any type of cell in the body. One of the main characteristics of stem cells is their ability to self-renew or multiply while maintaining the potential to develop into other types of cells. Stem cells can become cells of the blood, heart, bones, skin, muscles, brain etc. There are different sources of stem cells but all types of stem cells have the same capacity to develop into multiple types of cells.

Foetal stem cells

These are obtained from tissues of a developing human foetus. There are stem cells in the both placenta and blood contained in the placenta. These cells have some characteristics of the tissues they are taken from. For example, those taken from fetal muscles can make only muscle cells.

Adult stem cells

These are obtained from some tissues of the adult body. The most commonly used example is the bone marrow. Bone marrow is a rich source of stem cells that can be used to treat some blood diseases and cancers.

Discovery of stem cells

Scientists first studied the potential of stem cells in mouse embryos over two decades ago. Over years of research they discovered the properties of these stem cells in 1998. They found methods to isolate stem cells from human embryos and grow the cells in the laboratory.

Early studies utilized embryos created for infertility purposes through in-vitro fertilization procedures and when they were no longer needed for that purpose. The use required voluntary donation of the embryos by the owners.

Potential for use

Stem cell research is improving by leaps and bounds. These may soon become the basis for treating diseases such as Parkinson's disease, diabetes, heart failure, cerebral palsy, chronic ailments, spinal cord injuries, replacement or repair of damaged organs and reduced risk of transplantation.

Stem cells may also be used for screening new drugs and toxins and understanding birth defects without subjecting human volunteers to the toxins and drugs.

Others have the potential to repair or replace damaged tissue or cells. Embryonic stem cells are developed from a female egg after it is fertilized by sperm. The process takes 4-5 days.

By Dr Ananya Mandal, MD

WHAT IS STEM CELL RESEARCH?

Stem cell research is used for the investigation of basic cells which develop organisms. The cells are grown in laboratories where tests are carried out to investigate fundamental properties of the cells.

There are stem cells in the both placenta and blood contained in the placenta. However, aborted fetuses are not the only source of stem cells

The controversy surrounding stem cell research led to an intense debate about ethics. Up until the recent years, the research method mainly focused on embryonic stem cells, which involves taking tissue from an aborted embryo to get proper material to study. This is typically done just days after conception or between the 5th and 9th week.

Since then, researchers have moved on to more ethical study methods, such as adult somatic cells, which is probably an important advancement in stem cell research.

Objections to stem cells:

“We should not mess with human life.”

“Humans should not be trying to play God”

“Stem cell research in the far future can lead to knowledge on how to clone humans. It is hard to say whether this is true, but there have been devastating consequences of other research-programs, even with good intentions (for instance: nuclear research)”.

From “The Church opposes science”:

“Dawkins is also mistaken that the Church obstructs vital stem cell research. The Church opposes research — stem cell or otherwise — that involves the intentional killing of human embryos. Stem cell research that does not involve killing embryos is not only permitted by the Church but even funded by the Church, which has held at least two international conferences on stem cell research and has also funded research on adult stem cells undertaken at the University of Maryland School of Medicine. This research, using stem cells from adults or umbilical cords, has actually been developed into treatments that have already saved human lives. To date, despite billions of dollars, embryonic stem cell research has not led to one cure or a single effective treatment. The Church does not oppose stem cell research as such, but only opposes any kind of research that involves killing humans.”

Christopher Kaczor

WHAT IS GENE THERAPY?

Gene therapy is an experimental technique that uses genes to treat or prevent disease. In the future, this technique may allow doctors to treat a disorder by inserting a gene into a patient's cells instead of using drugs or surgery. Researchers are testing several approaches to gene therapy, including:

- Replacing a mutated gene that causes disease with a healthy copy of the gene.
- Inactivating, or “knocking out,” a mutated gene that is functioning improperly.
- Introducing a new gene into the body to help fight a disease.

Although gene therapy is a promising treatment option for a number of diseases (including inherited disorders, some types of cancer, and certain viral

infections), the technique remains risky and is still under study to make sure that it will be safe and effective. Gene therapy is currently only being tested for the treatment of diseases that have no other cures.

Currently there no a cure for genetic disorders, and treatment is only indicative. This is why there is so much turmoil in the medical arena about the possible effects of gene therapy. Somatic cells involve targeting somatic cells for gene replacement, while reproductive cell therapy involves replacing defective genes in reproductive cells with correct genes. Changes made in the genetic make-up of somatic cells is only corrective for the patient. Alterations are, however, not inherited by offspring of the treated person.

PROS OF GENE THERAPY

1. Replace Defective Cells

Humans have always been prone to variety of diseases. Although many of such diseases can be treated or cured medically, there is no cure for genetic disorders unless defective cells are replaced by proper ones which is what gene therapy does.

2. Eradicate Disease

Targeting reproductive cells can get rid of defects for good. People with genetic disorders such as Alzheimer's disease, Huntington's disease and Parkinson's disease are among those who require gene therapy.

CONS OF GENE THERAPY

1. Modify Human Capabilities

It may be used to enhance and modify human capabilities. If this was feasible, standards for normal human life would be altered for good.

2. Damage Gene Pool

If gene therapy was performed to a certain degree, it possibly could permanently change the human gene pool.

3. Rise in Disorders

If there is an error in the process, the result could be bring about severe disorders.

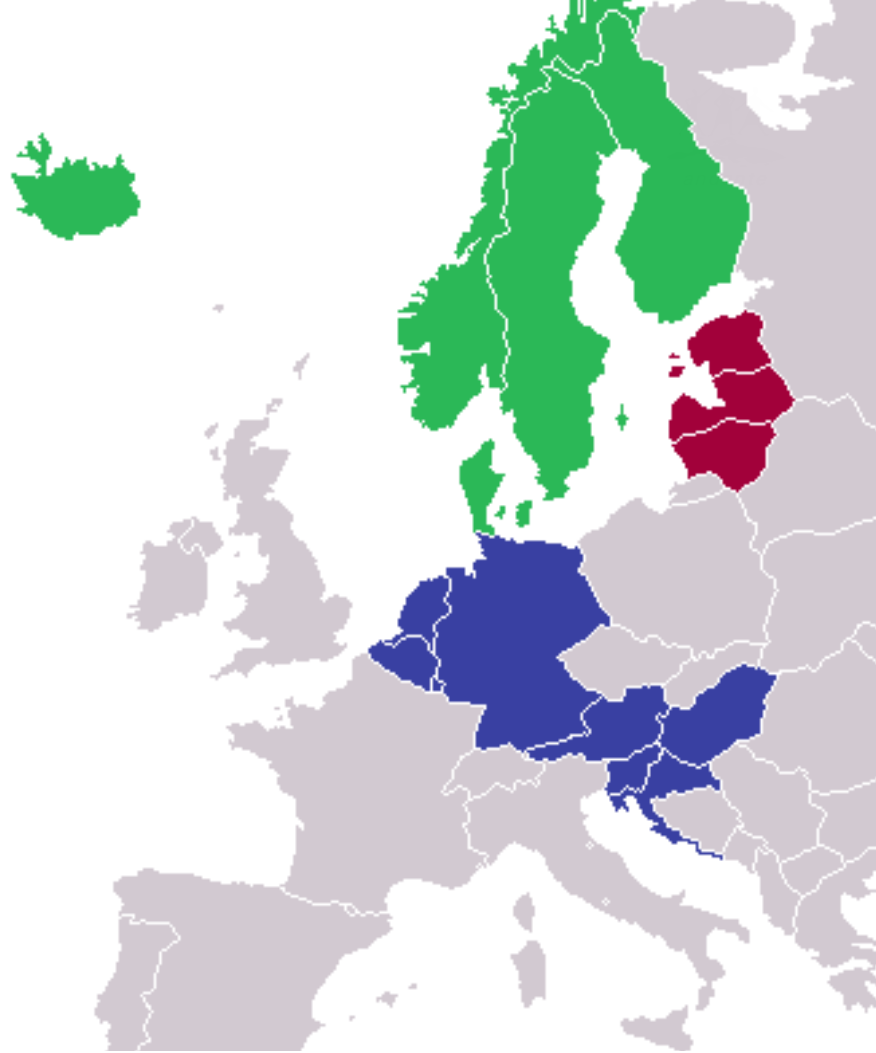
Source:Learn.genetics

ORGAN DONATION

is the **donation** of biological tissue or an **organ** of the human body, from a living or dead person to a living recipient in need of a **transplantation**.

Within the European Union, organ donation is regulated by member states. As of 2010, 24 European countries have some form of presumed consent. In 2008, the European Parliament overwhelmingly voted for an initiative to introduce an EU organ donor card in order to foster organ donation in Europe.

Not only does the Church accept the transplanting of human organs, it recognizes the donation of organs and blood to those in need as acts of charity and therefore commendable. Such donations must not in the slightest way cause the death of the donor.



Map showing the coverage of 3 international European organ donation associations: Baltransplant, Eurotransplant and Scandiatransplant

Source: wikipedia

EUTHANASIA

is the act of deliberately ending a person's life to relieve suffering.

For example, a doctor who gives a patient with terminal cancer an overdose of muscle relaxants to end their life would be considered to have carried out euthanasia.

Assisted suicide

is the act of deliberately assisting or encouraging another person to kill themselves.

If a relative of a person with a terminal illness were to obtain powerful seda-

tives, knowing that the person intended to take an overdose of sedatives to kill themselves, they may be considered to be assisting suicide.

Euthanasia can be classified in different ways, including:

- **active euthanasia** – where a person deliberately intervenes to end someone's life – for example, by injecting them with a large dose of sedatives
- **passive euthanasia** – where a person causes death by withholding or withdrawing treatment that is necessary to maintain life, such as withholding antibiotics from someone with pneumonia



Euthanasia can also be classified as:

- **voluntary euthanasia** – where a person makes a conscious decision to die and asks for help to do this
- **non-voluntary euthanasia** – where a person is unable to give their consent (for example, because they are in a coma or are severely brain damaged) and another person takes the decision on their behalf, often because the ill person previously expressed a wish for their life to be ended in such circumstances
- **involuntary euthanasia** – where a person is killed against their expressed wishes

Depending on the circumstances, voluntary and non-voluntary euthanasia could be regarded as either voluntary manslaughter (where someone kills another person, but circumstances can partly justify their actions) or murder. Involuntary euthanasia is almost always regarded as murder.

There are arguments used by both supporters and opponents of euthanasia and assisted suicide.

FOR:

- **ethical argument** – that people should have freedom of choice, including the right to control their own body and life (as long

as they do not abuse any other person's rights), and that the state should not create laws that prevent people being able to choose when and how they die

- **pragmatic argument** – that euthanasia, particularly passive euthanasia, is allegedly already a widespread practice, just not one that people are willing to admit to, so it is better to regulate euthanasia properly.

AGAINST

- **religious argument** – that these practices can never be justified for religious reasons; for example, many people believe that only God has the right to end a human life
- **'slippery slope' argument** – this is based on the concern that legalising euthanasia could lead to significant unintended changes in our healthcare system and society at large that we would later come to regret
- **medical ethics argument** – that asking doctors, nurses or any other healthcare professional to carry out euthanasia or assist in a suicide would be a violation of fundamental medical ethics
- **alternative argument** – that there is no reason for a person

to suffer either mentally or physically because effective end of life treatments are available; therefore, euthanasia is not a valid treatment option, but represents a failure on the part of the doctor involved in a person's care

Different practices

Both euthanasia and assisted suicide are illegal under English law.

Depending on the circumstances, euthanasia is regarded as either manslaughter or murder and is punishable by law, with a maximum penalty of up to life imprisonment.

Assisted suicide is illegal under the terms of the Suicide Act (1961) and is punishable by up to 14 years' imprisonment. Attempting to kill yourself is not a criminal act in itself.

Active euthanasia is currently only legal in Belgium, The Netherlands and Luxembourg. Under the laws in these countries, a person's life can be delib-

erately ended by their doctor or other healthcare professional.

However, euthanasia is only legal if the following three criteria are met:

- The person has made an active and voluntary request to end their life.
- It is thought that they have sufficient mental capacity to make an informed decision regarding their care.
- It is agreed that the person is suffering unbearably and there is no prospect for an improvement in their condition.

In some countries the law is less clear, with some forms of assisted suicide and passive euthanasia legal, but in Europe active euthanasia is illegal.

For example, some types of assisted suicide and passive euthanasia are legal in Switzerland, Germany, Mexico and five American states.

Source: NHS Choices

ASSISTED SUICIDE: A RIGHT OR A WRONG?

By Claire Andre and Manuel Velasquez

Matthew Donnelly loved life. But Matthew Donnelly wanted to die. For the past thirty years, Matthew had conducted research on the use of X-rays. Now, skin cancer riddled his tortured body. He had lost his nose, his left hand, two fingers on his right hand, and part of his jaw. He was left blind and was slowly deteriorating. The pain was unrelenting. Doctors estimated that he had a year to live. Lying in bed with teeth clenched from the excruciating pain, he pleaded to be put out of his misery. Matthew wanted to die now.

His pleas went unanswered. Then, one day, Matthew's brother Harold, unable to ignore Matthew's repeated cry, removed a .30 caliber pistol from his dresser drawer, walked to the hospital, and shot and killed his brother. Harold was tried for murder.

Rapid and dramatic developments in medicine and technology have given us the power to save more lives than was ever possible in the past. Medicine has put at our disposal the means to cure or to reduce the suffering of people afflicted with diseases that were once fatal or painful. At the same time, however, medical technology has given us the power to sustain the lives (or, some would say, prolong the deaths) of patients whose physical and mental capabilities cannot be restored,



whose degenerating conditions cannot be reversed, and whose pain cannot be eliminated. As medicine struggles to pull more and more people away from the edge of death, the plea that tortured, deteriorated lives be mercifully ended grows louder and more frequent. Californians are now being asked to support an initiative, entitled the Humane and Dignified Death Act, that would allow a physician to end the life of a terminally ill patient upon the request of the patient, pursuant to properly executed legal documents. Under present law, suicide is not a crime, but assisting in suicide is. Whether or not we as a society should pass laws sanctioning "assisted suicide" has generated intense moral controversy.

Supporters of legislation legalizing assisted suicide claim that all persons have a moral right to choose freely what they will do with their lives as long as they inflict no harm on others. This right of free choice includes the right to end one's life when we choose. For most people, the right to end one's life is a right they can easily exercise. But there are many who want to die, but whose disease, handicap, or condition renders them unable to end their lives in a dignified manner. When such people ask for assistance in exercising their right to die, their wishes should be respected.

Furthermore, it is argued, we ourselves have an obligation to relieve the suffering of our fellow human beings and to respect their dignity. Lying in our hospitals today are people afflicted with excruciatingly painful and terminal conditions and diseases that have left them permanently incapable of functioning in any dignified human fashion. They can only look forward to lives filled with yet more suffering, degradation, and deterioration. When such people beg for a merciful end to their pain and indignity, it is cruel and inhumane to refuse their pleas. Compassion demands that we comply and cooperate.

Those who oppose any measures permitting assisted suicide argue that society has a moral duty to protect and to preserve all life. To allow people to assist others in destroying their lives violates a fundamental duty we have to respect human life. A society committed to preserving and protecting life should not commission people to destroy it.

Further, opponents of assisted suicide claim that society has a duty to oppose legislation that poses a threat to the lives of innocent persons. And, laws that sanction assisted suicide inevitably will pose such a threat. If assisted suicide is allowed on the basis of mercy or compassion, what will keep us from "assisting in" and perhaps actively urging, the death of anyone whose life we deem worthless or undesirable? What will keep the inconvenienced relatives of a patient from persuading him or her to "voluntarily" ask for death? What will become of people who, once having signed a request to die, later change their minds, but, because of their conditions, are unable to make their wishes known? And, once we accept that only life of a certain quality is worth living, where will we stop? When we devalue one life, we devalue all lives. Who will speak for the severely handicapped infant or the senile woman?

Finally, it is argued that sanctioning assisted suicide would violate the rights of others. Doctors and nurses might find themselves "pressured" to cooperate in a patient's suicide. In order to satisfy the desires of a patient wanting to die, it's unjust to demand that others go against their own deeply held convictions.

The case for assisted suicide is a powerful one--appealing to our capacity for compassion and an obligation to support individual choice and self-determination. But, the case against assisted suicide is also powerful for it speaks to us of a fundamental reverence for life and the risk of hurling down a slippery slope toward a diminished respect for life. With legislation in the offing, we're compelled to choose which values are most important and to cast our vote.

CHANGING THE HUMAN PERSON: (SOME CONCEPTS)

Human enhancement (HE) refers to any attempt to temporarily or permanently overcome the current limitations of the human body through natural or artificial means.

Smaller or greater changes – at present or in the future:

Cosmetics (also known as make-up) are care substances used to enhance the appearance or odor of the human body. They are generally mixtures of chemical compounds, some being derived from natural sources and many being synthetics.

The Andante Summer School with the theme: “Why bioethics? – Bio-ethical issues facing people today” will take place from 12th to 16th August, 2015 in Vienna, Austria. For information and registration, please, go to the Andante website: andante-europa.net

Implant is something that is placed, usually surgically, within a living body, as grafted tissue or a medical device, such as a pacemaker or teeth.

Body modification (or body alteration) is the deliberate altering of the human anatomy or human physical appearance. It is often done for aesthetics, sexual enhancement, rites of passage, religious beliefs, to display group membership or affiliation, to create body art, for shock value, and as self-expression, among other reasons.

Sex reassignment surgery is the surgical procedure (or procedures) by which a transgender person's physical

appearance and function of their existing sexual characteristics are altered to resemble that of their identified sex.

Neurostimulation is a therapeutic activation of part of the nervous system using microelectrodes. The electrodes are used to interface with excitable tissue in order to either restore sensation, such as a cochlear implant for hearing, or control an organ, such as a heart pacemaker.

Neuropharmacology is the use of new chemicals which enhance the mental functioning or change mood and personality

Genetic engineering is the process of manually adding new DNA to an organism. The goal is to add one or more new traits that are not already found in that organism.

Source: wikipedia



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