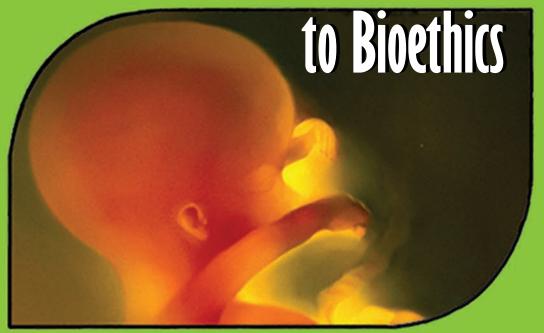
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Jérôme Lejeune FOUNDATION research, care, advocacy

Jérôme Lejeune Foundation, USA 6397 Drexel Road Philadelphia, PA 19151 www.lejeuneusa.org

# A Student's Guide



Jérôme Lejeune FOUNDATION research, care, advocacy A Student's Guide to Bioethics\_052213\_Students Guide to Bioethics 5/22/13 2:21 PM Page 3

# A Student's Guide to Bioethics





who we are.

hat is man, that you are mindful of him?" These words written over 3,000 years ago reflect a question that remains on our minds today. It is a very natural thing to question the purpose of our existence and to look at ourselves and all of our human potential with wonder and amazement.

There are many voices in our culture today, regrettably, that try to devalue human life and convince us that we are no different from other animals. Since 1972, abortion has been legal in the United States, and some states have made it legal for doctors to offer patients drugs to end their lives. Our culture seems to be telling us that babies, before they are born, are somehow not a part of the human family, and that the elderly and sick are no longer of value. In society today, our humanity is defined by what we can do, rather than by

But if we reflect on the question "What is man, that you are mindful of him?," we will come to know who we are—that we are much more than just another animal. In coming to know ourselves, we will also understand that there must be just laws to preserve the moral order and to protect humanity from exploitation and abuse.

Dr. Jérôme Lejeune was famous for his thought-provoking quotations, and one of them goes like this: "At universities, I have often seen extremely intelligent people holding conferences, nodding as they considered whether their children were some sort of animal when they were very young. But at the zoo, I have yet to see a conference of chimpanzees considering whether their children would grow up to be college professors!"

We are by our nature people of wonder. As Lejeune also said, "The absolute superiority, the complete novelty of humanity, is that no other creature can experience a kind of complicity between the laws of nature and its awareness of its own existence. ... Never in the history of gardening have we seen a dog smell the scent of a rose. Nor has a chimpanzee ever gazed at the sunset or the splendor of a starry sky."

Something clearly sets us apart from the rest of creation. It is in the awareness of this fact that we discover our human dignity. We are not mere animals. We are created with an almost infinite human potential for good and for evil.

There are many difficult questions today that we must be prepared to answer as we consider the meaning of our humanity and how we can live humanely in a culture that constantly places before us choices between good and evil. In a very real sense, science is the tree of good and evil planted in our modern Eden. We must learn from our first parents the responsibility to gather the good fruit and not to eat the bad.

This little handbook on bioethics is intended to help you distinguish the good fruit from the bad. With a scientific, factual approach, this handbook proposes ways that you can reflect on the consequences of choices that our culture has set before us.

Some of you may be surprised to discover the great responsibility the gift of our sexuality imposes on us with regard to the transmission of new life. In most textbooks, and certainly in our current cultural attitudes, procreation is not considered an obligation of marriage, and sexual activity is no longer seen as a loving expression of a unique and permanent bond between a man and a woman—a bond that civilization for thousands of years has called



marriage. The more that sexual activity becomes disassociated from the responsibility of marriage, the more unwanted pregnancies occur, and the louder the cry for a woman's "right" to abortion. The devaluation of life through abortion has also resulted in our accepting the killing of human embryos so that we can use their stem cells for scientific research.

The disassociation of procreation from marriage has also become, in some people's minds, a rationale for allowing people of the same sex to marry despite the fact that this unique and special relationship has been acknowledged since the beginning of time as only possible between a man and a woman.

As you begin to read this small book on bioethics, we ask that you keep two important questions in mind: is everything that is possible to do, ethical to do; and if something is legal in society, does that mean it is just?

We hope these pages will help you improve your understanding of bioethical issues that you must address as young adults. Even more, we hope this small book helps you reflect more deeply on the question "What is man that you are mindful of him?" In the end, the answer to all the questions presented here is found in your response to this fundamental question.

JEAN-MARIE LE MÉNÉ
PRESIDENT, JÉRÔME LEJEUNE FOUNDATION, PARIS

JOHN M. HAAS, PH.D. CHAIRMAN, JÉRÔME LEJEUNE FOUNDATION, USA

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In each chapter you will find the following sections:

- Discussion of the topic
- Legislation
- Frequently asked questions
- Ethical reflections
- Testimonies



# I / The story of a little human being

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The story of a human being starts with **fertilization**.

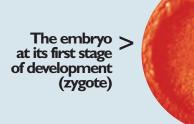
The zygote is the first stage of the **embryo**, in which 23 chromosomes from the mother combine with 23 chromosomes from the father. The embryo is 0.15 millimeters wide.

A new human life begins at the moment when the genetic information contributed by the sperm from the father is combined with the genetic information contributed by the ovum (egg cell) from the mother. As soon as fertilization is completed, a new human being begins his or her life.

The person's unique genetic inheritance, and therefore his or her sex, is determined at that moment. This is not a hypothetical human being but rather the first stage of development of someone who will later be named Paul or Virginia.

The zygote gets its genetic information and life from the father's live sperm and from the mother's live ovum.

The embryo begins to divide as it manifests a new, autonomous life.





2 cells



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# This embryo is an **Organism**, a **living being** with a **human** genetic inheritance. Therefore it is in fact a **human being**.

Then the embryo divides into 2, 3, 4, 8, and more cells. Signals go back and forth among the cells, showing that the embryo is organizing itself. From the zygote to the fetus, everything takes place in an orderly fashion. The process is continuous.



4 cells

2 days



8 cells 3 days



10 to 30 cells

4 days

Morula ("little mulberry")



5 to 7 days

Blastocyst implantation in the mother's uterus



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# **Pregnancy** is the condition of a woman who has conceived; it lasts from the time of fertilization to delivery.

The term of a pregnancy is calculated in two ways:

- In months of the embryo's development, starting from the day of fertilization
- In weeks without menstruation, counting from the first day of the last period

If a woman's cycle is 28 days, fertilization takes place on the 14th day.

When a woman realizes that she is pregnant because her period is late, her baby is already at least 14 days old.

At 21 days, her baby's heart will start beating.



1st day

Zygote



The baby at 5 weeks (3–5 mm)

1st month

The baby's heart beats. You can hear it on an ultrasound.



At 7 weeks (17–22 mm)

2nd month

The limbs form. Fingers, mouth, nose, ears, eyes, and even eyelashes can be distinguished.



At 8 weeks (35 mm)

The embryo is called a fetus.
The brain and other organs
are complete and functioning.



At 11 weeks (6 cm, 20 g)

3rd month

The baby moves his hands and feet.
His sex can be determined.



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At 16 weeks (20 cm, 250 g)

#### 4th month

He sucks his thumb and swallows the amniotic fluid. His hands are completely formed.



At 20 weeks (30 cm, 650 g)

#### 5th month

His mother feels him moving.



At 24 weeks (37 cm, 1,000 g)

#### 6th month

He moves a lot. He begins to react to exterior sounds.

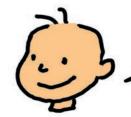


"The offspring

Jérôme Lejeune

#### 8th month

He assumes the position that he will stay in until delivery.



The embryo is human!



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# Frequently asked questions

# •• Isn't the embryo just a clump of cells?

No. Some people talk about a "clump," or a "mass," as opposed to an "organism." Yet from the start, the embryo is a living being that organizes itself through a process of continuous development.

The point at which the sperm penetrates the ovum determines the position of the head and feet in the developing embryo.

From the moment of fertilization, a series of events (the expression of the embryo's genetic code, the synthesis of proteins) is launched with a view to the embryo's development. For example, the embryo produces hormones that stop the menstrual cycle of his mother and begin to prepare her breasts for nursing. So no, it is not a clump of cells.

#### Is it a human being from the moment of fertilization?

Yes, because a man and a woman cannot conceive anything other than a little human being. Yes, because the unique human genetic inheritance of a person is determined at that precise moment. If the human being does not begin at the moment of fertilization, it never begins, because where would any new information come from? Even the term "test-tube baby" shows that this is universally recognized.

### •• It's a human being, but is it a person?

Yes. How can a human being not be a person? Historically, the only human beings who were not considered persons were slaves. If we decide that some human beings are not persons, then what kind of society do we live in?

#### Is believing the embryo is a human being just a personal opinion?

No. To agree that fertilization is the start of a new human being is not a matter of taste or opinion; it is a biological reality.

All the scientific evidence points in this direction and nothing can prove the contrary. No one can honestly doubt it.



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#### What makes a human embryo a human being?

A being is human not because of its qualities, abilities, or accomplishments but only because of its nature. He or she belongs to the **human species**, to the family of mankind, of all men and women, just like every one of us. He or she is therefore a human being.

# Does the embryo or fetus feel pain?

Yes. Today we know that the fetus feels pain starting in the second trimester of pregnancy. Some states in the United States have passed fetal pain legislation, which requires anesthesia to be administered to the fetus before abortion.

#### The embryo depends on his mother, so is he a human being?

Yes. Like any living being, the embryo needs a suitable environment in order to grow. We are all dependent at all stages of human life. We all need food and oxygen. Would any one of us survive naked in Antarctica? That does not make us any more or less human. Dependence, to whatever extent, does not change one's nature.

The fact that he is sheltered and nourished in his mother's body does not make a child in the womb part of the mother's body. He is different from her in every one of his cells.

#### If the embryo doesn't look human, is he a human being?

Yes. A human being is recognized not only by his appearance. Furthermore, the same individual over the course of a lifetime assumes different appearances as an embryo, baby, child, adult, and old person. The embryo looks like a human being looks at that age. We all passed through these developing embryonic forms, during which everything was already inscribed, even the color of our eyes!



Contrary to what you may read in some school textbooks, pregnancy begins when the sperm and egg join (fertilization), even though the woman is not aware of it until after the embryo attaches itself to the wall of the uterus (implantation).



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Abortion is the premature death of the embryo or fetus during his development. We talk about spontaneous abortion or miscarriage when the death is not caused deliberately. We talk about induced abortion or direct abortion when someone voluntarily puts an end to the life of the embryo or fetus.

The expression "termination of pregnancy" masks the reality that is the death of the child, the one who is most directly interested in living.

Under all state laws, women in the United States are allowed to choose to abort their fetuses before they are viable (meaning before the fetus can survive outside the womb), at about 24 to 28 weeks or within the first trimester (that is, three months) of pregnancy. After that, states are allowed to restrict abortions as long as they allow "medically indicated" ones, an ideologically loaded expression but one that suggests the mother's life or health is in danger.

In the United States, statistics show that over 1 million abortions are performed every year, and there have been over 50 million abortions in the United States since the procedure was legalized in 1973. Worldwide, there are around 50 million abortions every year. These millions of children were unique and irreplaceable.

#### **WARNING**

This chapter may shock some of you.

Since abortion is a violent reality, even a discreet description of it may offend some people. But in order to understand what is at stake, it is necessary to talk about it. We have tried to present this reality plainly, while choosing not to depict aborted fetuses.



## Methods

#### **Suction**

The fetus is dismembered by aspiration (suction). This method is commonly used for elective abortions.

#### **Partial birth**

This allows live nerve cells to be obtained from the fetus for research. The process is too graphic to describe here.

# RU-486 pill

the uterus.

**Dilation and** 

The embryo is destroyed with

a surgical instrument and his

remains are removed from

curettage

This pill makes the lining of the uterus unsuitable for the survival of an already implanted embryo.

#### Injection

- Potassium chloride is injected into the heart of the fetus, killing him and causing premature delivery.
- A hypertonic solution (a solution with a higher salt concentration than in the cells of the baby's body) is injected into the amniotic fluid, which then kills the baby within a few hours. Twenty-four hours after his death, the mother delivers the stillborn child. This type of abortion is used for so-called medically indicated abortions up to the ninth month of gestation.

#### Morning-after pill/ "emergency contraception"

If taken at a certain time in the menstrual cycle, this pill prevents fertilization and has a contraceptive effect. It is also possible, however, that it acts by preventing the implantation of an embryo that has already been conceived, thus aborting it.

#### **Intrauterine device**

An intrauterine device is placed in the uterus to prevent pregnancy. It is contraceptive because it is a chemical obstacle to sperm; it can but does not always prevent sperm from reaching the ovum. It also causes an abortion when a sperm cell nonetheless manages to reach the ovum and fertilize it: then the intrauterine device mechanically prevents the embryo from implanting in the uterus.



An intrauterine device and the morning-after pill can cause abortions when they prevent the implantation of the embryo.



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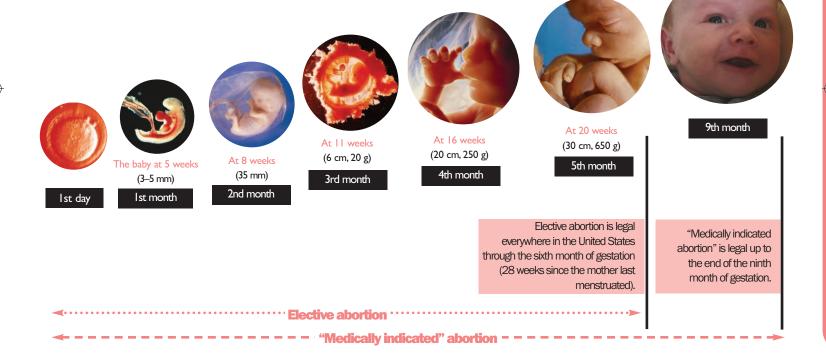
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# **Abortion timetable**





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## Legislation

According to Loxafamosity Ministries (Abort73.com), in a 2012 article on abortion legislation in the United States,

Abortion has never enjoyed such universal protection under the law as it has since 1973. As it stands today, American women have the legal right to obtain an abortion in all 50 states, through all nine months of pregnancy, for virtually any reason at all. This has been true since the Supreme Court declared that autonomous abortion rights are built into the Constitution, and that any legal barriers which prevent mothers from aborting their children are unconstitutional. This ruling was arrived at on the premise that the 9th and 14th Amendments, according to legal precedent established during the 1960s, guarantee a woman's "right to privacy," a right that extends even to abortion.

The opportunity to make such a sweeping declaration came via two cases that both presented constitutional challenges to state criminal abortion laws. One case came from Texas and the other from Georgia. The Texas case, Roe v. Wade, involved a pregnant, single woman, "Roe," who was suing the Dallas County district attorney, Henry Wade, to prevent him from enforcing Texas's abortion prohibition. Since her life was not threatened by her pregnancy, she had no legal basis for aborting in Texas. (Prohibitive abortion laws had existed in Texas with very little change since 1854 but had always included an exception to save the life of the mother.) The Georgia case, Doe v. Bolton, involved a married woman who was also denied an abortion for not meeting the necessary state requirements. (Georgia law allowed for abortion if the life or health of the mother was threatened, if the baby was seriously deformed, or if the pregnancy was a result of rape.) A three-judge District Court ruled that Roe did have the basis to sue, and declared Texas abortion law void for being "vague" and "overbroad." The District Court ruling in the Doe case was split. It ruled that there were some unnecessary bureaucratic burdens that might hinder someone from receiving a due abortion, but it still held that the State had a right to restrict abortion according to the principles already in place. Both decisions were appealed, both decisions ended up before the Supreme Court, and both verdicts were handed down on the same day, January 22, 1973. ("U.S. Abortion Law: An Overview of the History and Legality of Abortion in the United States," June 28, 2012, http://www.abort73.com/abortion\_facts/us\_abortion\_law/).

There have been numerous challenges to *Roe v. Wade* since 1973, but in almost every case the Supreme Court has upheld its initial ruling and rejected even the most reasonable restrictions:

In 1976, abortion again made its way to the Supreme Court, in Planned Parenthood v. Danforth, where all state laws requiring spousal or parental consent were thrown out. Thornburg v. American College of Obstetricians and Gynecologists, a 1986 case that was split 5-4, struck down all manner of abortion restrictions, including the requirement to inform women about abortion alternatives, the requirement to educate women about prenatal development, the requirement to inform women of the potential risks of abortion, the requirement to keep records of abortion, and the requirement that 3rd trimester abortions be performed in such a way as to spare the life of the viable child. All these were argued to be violations of a woman's right to privacy. In 1989, however, in Webster v. Reproductive Health Services, Roe was dealt a serious blow. The court, in a 5-4 opinion, let stand a Missouri statute stating that human life begins at conception, and declared that the state does have a "compelling" interest in fetal life throughout pregnancy. The trimester/viability framework of Roe was basically thrown out, but Justice [Sandra Day] O'Connor, despite arguing for essentially the same thing in prior case law, withheld her endorsement from the portion of the Webster opinion that would have actually overturned Roe. As such. federal abortion laws remained largely unchanged, but the rationale for such laws began to crumble (ibid.).



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## Frequently asked questions

# If you are pregnant and alone, who can help?

# A pregnant woman, especially if she is alone, can be fearful and dejected and may feel overwhelmed by the situation. She needs to be listened to, supported, and sometimes helped financially. Although elective abortion may seem to her to be the best option in a bad situation, she should know that many women painfully regret their abortions and regret not having chosen life and love for their children. To lessen her fear and loneliness, she should know that groups are there to help and guide her.

# Should a woman get help?

A woman thinking about having an abortion needs someone to listen to her.

After an abortion, a woman must get help, because she may be alone and have feelings of guilt. She must be able to shape her future while including this event in it.

# Does abortion have psychological consequences?

Yes. Many women who have aborted show signs of depression and other disorders, including guilt, loss of self-esteem, suicidal thoughts, anxiety, insomnia, anger, sexual troubles, and nightmares about her baby. A woman who has aborted a child may not make the connection of the symptoms to her abortion. These consequences, which can appear right away or much later, are now well known and are identified as "post-abortion syndrome." These symptoms are intensified every time the mother meets a pregnant woman, sees a baby, passes by an abortion facility, or thinks of the anniversary of her baby's death.

Post-abortion syndrome is not limited to the mother. It is possible for it to extend to those close to her: the father, brothers and sisters, and others.

Women around the world are starting to give witness: "If only we had known."

For more information on post-abortion syndrome, see **silentnomoreawareness.org**.

Women in difficult situations can get help from specialized counselors and groups that provide help.

#### For free and anonymous help:

Pregnancy Help Hotline: **1-800-395-4357** (call 24 hours a day, 7 days a week)

Birthright • 1-800-550-4900 • www.birthright.com

Pro-Life on Campus • www.prolifeoncampus.com/crisis-pregnancy-help



According to Loxafamosity Ministries,

Roe ruled (7-2) that though states did have an interest in protecting fetal life, such interest was not "compelling" until the fetus was viable (placing viability at the start of the 3rd trimester). Thus, all state abortion laws that forbade abortion during the first six months of pregnancy were thereby invalidated. Third trimester abortions were declared to be legal only if the pregnancy threatened the life or health of the mother. The Doe verdict, however, defined "health of the mother" in such broad terms that any prohibitions to 3rd trimester abortions were essentially eliminated. According to Justice Harry Blackmun's majority opinion, a woman's health includes her "physical, emotional, psychological, (and) familial" well-being, and should include considerations about the woman's age. "All these factors may relate to health," Blackmun argued, so as to give "the attending physician the room he needs to make his best medical judgment." In other words, if a woman is upset about her 3rd-trimester pregnancy (psychological health), her doctor has the necessary legal basis to abort. ("U.S. Abortion Law: An Overview of the History and Legality of Abortion in the United States." June 28, 2012. http://www.abort73.com/abortion\_facts/us\_abortion \_law/.)

## Is abortion right?

Direct abortion is the willful taking of a human life. It allows those with power to determine who lives and who dies. In no circumstances is it okay to kill another human being. Remember, **"Thou shalt not kill."** 



# Easy-to-remember statistics

- The number of abortions in the United States is about **1.2 million a year**.
- •Using figures through 2008, estimating 1,212,400 abortions for 2009 through 2011, and factoring in a possible 3% undercount, Loxafamosity Ministries calculated that the total number of abortions performed in the United States since 1973 equals **54,559,615**. (www.abort73.com.)

At the age of 2 months, I measure 1.18 inches from top to bottom. With a microscope you can see my fingerprints!



**Camille and** 

her baby.

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## **Ethical reflections**

# Woman and child: friends or enemies?

Why should the mother's option to kill her child overrule the child's right to live? Can the child be considered as an unjust aggressor? Even though this theory has unfortunately been developed by some philosophers, **the child is always innocent**. The bond that unites the mother and her baby, which is the very symbol of love and peace, is terribly damaged by a law that allows abortion.

#### **Cases of rape**

It is understandable that a woman may not want the child of a rape. The mother needs special care after experiencing such trauma. But killing her child does not undo the tragedy; on the contrary, it aggravates it. The criminal must be punished, but why should the child, who is innocent, suffer the death penalty?

#### **Women's empowerment**

Some claim that abortion liberates a woman from the constraints of motherhood and gives her a "right to control her own body."

Biologically, though, the child is not a part of the mother's body: the child is a guest. Therefore the mother cannot dispose of the unborn.

Moreover, abortion is an attack on the very nature of woman, which is to be a mother. The immense suffering of sterility demonstrates what an essential part of the feminine identity that motherhood is.

Hence killing one's child cannot be the source of freedom or personal fulfillment.



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"A society that kills its children loses its soul and its hope at the same time."

Jérôme Lejeune

#### What about fathers?

It is not uncommon that young pregnant women feel obliged to abort because the father does not want to take responsibility for their child.

Conversely, it sometimes happens that women abort against the will of the child's father.

The father cannot oppose the mother's will and protect his child. Is it not, however, the child of them both? The child is "flesh of the flesh" of both of them through procreation.

A young 22-year-old father confided that he had nearly jumped out of a window when he learned that his girlfriend had aborted their child.

The law in the United States ignores the father's right to protect the "flesh of his flesh."

#### Choice

In choosing abortion, parents choose death for their child. Thus, current law gives parents the right to kill.

What is legal is not necessarily moral. Although the American justice system, since 1973, does not accuse parents for choosing to commit a deadly act through abortion, our conscience reminds us of the fundamental principle "Thou shalt not kill."

#### **Money problems**

Are financial problems sufficient reason to terminate a pregnancy? The best way to help a woman in a difficult situation is not to help her kill a life but rather to resolve her financial problems. If the mother cannot raise her child, adoption is another possible solution for her.

#### **Adoption**

In cases of extreme hardship, it may happen that a mother cannot raise her child. She can then entrust her baby to adoptive parents. Unlike abortion, in which the child loses everything, adoption gives him a chance: he loses his mother but keeps his life and finds new parents. In the United States, over 120,000 children are adopted each year.



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# **Abortion and contraception**

# The contraceptive mentality

The contraceptive mentality (the intention to not have children) leads to accepting abortion more readily as a solution to the "problem" of an "unwanted pregnancy."

# Does contraception prevent abortion?

It is often said that contraception is the most effective remedy against abortion. But is this true? No, for 3 reasons:

- 1. All contraceptive pills cause a percentage of early abortions.
- The contraceptive mentality leads to accepting abortion more readily in the case of an "unwanted pregnancy."
- Contraception encourages sexual relations with multiple partners in unstable relationships, which in fact increases the number of unintended pregnancies.

Statistics confirm that increased contraception use does not decrease the number of abortions.

#### The Pill and abortion

All contraceptive pills cause a percentage of early abortions. Indeed, the classic "combined," or estroprogestin, pills act as contraceptives when they block ovulation and modify the cervical mucus, making it hostile to sperm. But when one of these mechanisms is not enough (1 out of 10 times ovulation is not blocked), a third effect of the Pill takes over: the modification of the uterine lining to prevent the implantation of the embryo. This, then, is an abortive effect, since the embryo dies. The micro-dose pills and progestin contraceptives ("mini-pill," "morning-after pill," "emergency contraception." contraceptive shots, and implants of contraceptives under the skin) have the same effect. In these cases, the abortion takes place without the woman being aware of it.







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## **Testimony**

## **Abortion and peace**

If we allow the weakest to be killed in our own families, how can we ask nations that are enemies not to kill each other's citizens?

Abortion re-establishes the law of the strongest. **Accepting abortion counteracts peace.** 

"I feel the greatest destroyer of peace today is abortion, because it is a direct war, a direct killing—direct murder by the mother herself.... If a mother can kill her own child, what is left [but] for me to kill you and you kill me?"

**Mother Teresa of Calcutta** 

I was 22 years old. For 3 years I had been having a relationship with a student from my school. One night, since I had forgotten my pill, we used a condom that happened to tear. Two weeks later, my life was turned upsidedown: I was pregnant. ... From then on, the loneliness that I felt and the pressure from the child's father to abort were immense: he wanted nothing to do with the child. We fought violently for 6 days, then I gave in, too isolated and intimidated and without any support from my family. When I woke up there was nothing left: the world was empty. Ten days later I experienced 2 days of hemorrhaging. For the next 20 years, on the "anniversary" of that day, I have relived the anguish and the loneliness of that moment and I have had terrible stomach pains. At the birth of each of my children I experienced months of depression and terrible nightmares, that I was killing my baby with my own hands. Today, at age 40, not 1 day passes without my thinking about that child and about the part of myself that I killed in having an abortion.

Emma, a mom



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# What is prenatal testing?



Prenatal testing and diagnosis are a set of tests that are administered for the early detection of abnormalities of the fetus in the mother's womb.

It is part of monitoring pregnancies and is desirable to do as soon as possible because it can be useful in detecting certain anomalies for which the child can be treated early.

However, today prenatal testing has strayed from this purpose of protecting the health of mother and child. It is used most often to detect anomalies, such as trisomy 21, and the diagnosis frequently results in a decision to abort.

In utero operation at 21 weeks' gestation on Samuel, who has spina bifida. Samuel was born on December 2, 1999.



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In effect, abortion law allows the termination of pregnancy throughout all 9 months if there is a strong possibility that the fetus will suffer from a serious, incurable condition.

Societal pressure leads physicians to use prenatal testing not to care for the child but to recommend abortion. From the doctor's perspective, there is an insidious fear of overlooking an anomaly for which he will later be blamed, or possibly even sued for not having detected. Thus, this leads to an increase in the number of abortions resulting from an unexpected prenatal diagnosis. Today, prenatal testing serves all too often to monitor the "quality" of a preborn child and to eliminate him if he is not up to his parents' or society's expectations.



Karyotype: profile of a set of human chromosomes.





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## Methods

#### **Sonogram**

The sonogram is the main prenatal testing test. It allows medical personnel to see the baby by using computer-synthesized images. This exam is performed at least 3 times during a pregnancy (at 12, 21, and 33 weeks after menstruation stops). This is the test that is used to measure, among other things, the width of the nape of the neck, and check for signs of trisomy 21, a chromosomal anomaly in which there are 3 copies of chromosome 21 instead of 2 copies.

# Amniocentesis and chorionic villus sampling

Amniocentesis, performed after the end of the third month after menstruation stops, is a study of the fetal cells in the amniotic fluid with a view of determining the child's karyotype (a representation of the child's set of chromosomes). This delicate test accidentally causes the death of the fetus in more than 1% of the cases. Chorionic villus sampling, usually performed between 10 and 13 weeks' gestation, involves taking a biopsy of the placental tissue. This allows medical personnel to make a karyotype even earlier in pregnancy, during the first trimester. The risk of miscarriages is between 1% and 2%.

#### **Maternal blood tests**

Since 2011, a simple test of the mother's blood can detect some chromosomal abnormalities in the baby. These tests can be done as early as 10 weeks' gestation with no risk to the mother or child. They are almost 99% accurate.

#### **Screening for trisomy 21 (Down syndrome)**

Prenatal testing makes it possible to assess the risk that a fetus has trisomy 21. The diagnostic test consists of the analysis of the fetus's chromosomes from a sample obtained by an invasive procedure (amniocentesis or chorionic villi sampling), or from a noninvasive maternal blood test. Screening for trisomy 21 is based on the mother's age, blood levels of certain biochemical markers, and the thickness of the nape of the fetus's neck as measured sonographically. A 2002 literature review of elective abortion rates found that 91%-93% of pregnancies in the United Kingdom and Europe with a diagnosis of Down syndrome were terminated. In the United States, a number of studies have examined the abortion rate of fetuses with Down syndrome. Three studies estimated the termination rates at 95%, 98%, and 87%, respectively. With simplified diagnostic tests, the detection of trisomy 21 and other genetic abnormalities will become more and more commonplace. This could lead to almost complete eradication of children who have that genetic condition.



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A child with Down syndrome can legally be aborted up to birth in most countries.

# Legislation

The Genetics and Public Policy Center describes the lack of consistent regulation of reproductive technologies and prenatal genetic testing in the United States:

There is no uniform or comprehensive system for the regulation of assisted reproductive technologies, including reproductive genetic testing. The federal government does not have direct jurisdiction over the practice of medicine. Moreover, it has banned all federal funding for research involving the creation or destruction of embryos. Consequently, the regulatory framework for reproductive genetic testing in the United States is characterized by a patchwork of federal and state regulation. Professional self-regulation also plays a central role in the governance of this field. Federal oversight of these technologies is spread among several agencies, whose jurisdiction in the area of assisted reproductive technologies and genetic testing is derived from existing statutes having broader applicability.

Clinical Laboratory Improvement Amendments of 1988 (CLIA)

All laboratory tests performed for the purpose of providing health information to an individual must be conducted in laboratories certified under CLIA. CLIA requires the government to certify all laboratories performing testing to provide "information for the diagnosis, prevention, or treatment of any disease or impairment of, or the assessment of the health of, human beings." Tests are regulated according to their level of complexity: waived, moderate, or high complexity. The regulatory requirements applied to these laboratories increase in stringency with the complexity of the test performed. Under CLIA, the Health Care Financing Administration's (HCFA) Division of Laboratory Systems develops standards for laboratory certification. However, CLIA has no specific jurisdiction to regulate such aspects of genetic tests as clinical validity and utility, informed consent, or the provision of genetic counseling. Moreover, the Centers for Medicare and Medicaid Services (CMS), which administers CLIA, has taken the position that laboratories that perform [preimplantation genetic diagnosis] PGD are not considered "clinical laboratories" under CLIA.

Food and Drug Administration (FDA)

Under the Federal Food, Drug and Cosmetic Act, in vitro diagnostic products, i.e., products used to diagnose a disease or condition, are regulated as medical devices by FDA. However, not all products used by clinical laboratories to perform genetics testing are regulated as in vitro diagnostic products. In fact, FDA has limited oversight over the majority of tests used in PGD.

(Reproductive Genetic Testing: A Regulatory Patchwork [United States], http://www.dnapolicy.org/policy.international.php?action=detail&laws id=63.)



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# Frequently asked questions

# Are prenatal diagnostic techniques bad?

The techniques for prenatal testing are neither good nor bad in themselves; it all depends on how they are used. They can be good if they serve to detect conditions that can then be treated or if they help the parents get ready to welcome a sick child. But they are terrible if they are used to pick and choose among babies before birth.

Under the Patient
Protection and Affordable
Care Act ("Obamacare"),
the federal government
has endorsed and
encouraged prenatal
testing by requiring
insurers to cover 100% of
the cost of the tests.

#### Is prenatal testing the same as eugenics?

People frequently talk about prenatal testing in relation to eugenics because it is associated with "mass screening" and very often leads to an elective abortion. This is especially true of infants with Down syndrome, who are aborted about 90% of the time. Thus, a certain sort of medical practice, under cover of the law, has increasingly drifted away from health care into the business of eliminating persons because of their genetic heritage. This drift is reminiscent of the criminal methods that were used during certain historical periods to deal with mentally disabled persons.

## Do you have to get a prenatal test?

No. It is important to remember that tests are offered to women—they are not mandatory. Women should feel free to ask your health care provider why he or she is ordering a certain test, what the risks and benefits are, and, most important, what the results will—and won't—reveal.



#### What if I wasn't expecting a disabled child?

Every family has to be prepared to welcome a child, even a sick child. The shock of the announcement is harder for those who have never even thought about this possibility and have not decided in their hearts to welcome the child for his or her own sake.

Prenatal diagnosis has made Down syndrome, a non-fatal condition, deadly: most of the fetuses who are found to have trisomy 21 are aborted.

# Why not have an abortion, since my disabled child will not be happy?

In our culture, persons with disabilities are forced to prove that they are happy so as to have the right to live. Nobody can measure someone's degree of happiness. There are plenty of testimonies of persons afflicted with a serious disability who say that they are glad to be alive. A systematic study revealed that 99% of persons with trisomy 21 were happy with their lives, 99% of parents said they loved their child with trisomy 21, and 97% of brothers and sisters ages 9 to 14 said they loved their sibling with trisomy 21. (See Brian G. Skotko, Susan P. Levine, and Richard Goldstein, "Self-perceptions from People with Down Syndrome," American Journal of Medical Genetics, October 2011.)

### Who can judge the value of a human life?

Deciding to have an abortion because of an ailment or malformation in the fetus is judging the value of a human being's life: it is a judgment that because this fetus is afflicted with a serious ailment, his birth should be prevented and his life has less value than one's own.



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## **Ethical reflections**

#### **Suffering of parents**

Everybody, particularly physicians, should have compassion for parents of children with disabilities. But how can anyone think that you could ease the pain of a human being by killing another human being? Everything possible must be done to do away with the sickness of the child, not the sick child himself. As Jérôme Lejeune said, "Medicine is hatred for the sickness and love for the sick person." The loss of a child is always a tragedy.

"I am not a chromosomal anomaly. My name is Virginia." <sup>Virginia</sup>

#### A sickness in society?

Many parents suffer from the disapproving looks of people who see their child and blame them: "You wanted to keep that child? Don't ask society to take care of him!"

The state of California budgets over \$100 million each year for a prenatal testing program. Doctors are required to make prenatal testing available to patients, and the women must signify that they either accept or decline. The U.S. federal government budgets only about \$20 million for Down syndrome research. Western society is becoming more and more intolerant of disabilities, and "the myth of the perfect baby" is making headway.

#### "Wrongful birth"

There are 25 states that allow wrongful-birth lawsuits, in which the parents can sue a physician for not diagnosing Down syndrome or other disabilities in the child before his birth.

However, some states have statutorily banned wrongful-birth actions. For example, Idaho Code §5-334(1) reads, "A cause of action shall not arise, and damages shall not be awarded, on behalf of any person, based on the claim that but for the act or omission of another, a person would not have been permitted to have been born alive but would have been aborted."





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# **Testimony**

#### Éléonore's mom

Since Éléonore's birth 24 years ago, people have often asked me: "But why? Didn't you know that you were carrying a child with trisomy 21? Didn't they perform an amniocentesis?" At first I used to say, "No, I didn't know." Then I added, "I did not know, and it's just as well. If I had found out during my pregnancy, I would certainly have been afraid and made the biggest mistake in my life." Twenty-four years ago I knew nothing about Down syndrome—just a few preconceived ideas, most of them horrible sources of anguish, shame, and aversion. I would probably have preferred to terminate my pregnancy. Once the shock of the news about the handicap was over, Éléonore made us, her parents, aware of a strength and a capacity for tolerance that we had not recognized at all. Today we know how much Éléonore has enriched us by being different, how much she has contributed by her radiance, and how happy she is to be alive.

Today we look back on the extent of our ignorance 24 years ago, and more than ever we sigh, "How lucky we are that we did not know that the stranger I was carrying inside of me had Down syndrome."

Maryse Laloux, 2009

See www.lesamisdeleonore.com for more information.



Éléonore Laloux is the spokesperson for an advocacy group for persons with trisomy 21.



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# What is assisted reproductive technology?

Assisted reproductive technology (ART) usually means the set of techniques that make procreation possible apart from the natural process.

ART uses sperm cells from a man and egg cells from a woman.

There are two principal techniques of ART: artificial insemination and in vitro fertilization (IVF) with embryonic transfer.



Micro-injection of a sperm cell into an ovum with a pipette.



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## **Methods**

# Artificial insemination

- 1. Sperm is collected.
- 2. The sperm is introduced directly into the woman's cervix.
- The egg is fertilized in the woman's fallopian tube. The pregnancy then proceeds in the usual way.

#### In vitro fertilization

- Sperm is collected from the father, and several ova are collected from the mother.
- 2. The ova are brought into contact with the sperm in vitro (in a petri dish). Fertilization takes place. Several embryos start to grow.
- 3a. Several embryos are created, but usually only 1 to 3 are transferred into the mother's uterus. Then pregnancy proceeds as usual, unless there are complications. Multiple pregnancies (twins, triplets, and such) are common. However, with a multiple pregnancy that results from IVF, often one or more of the embryos are then killed in a process called "embryo reduction."
- 3b. The embryos conceived but not transferred are either destroyed if they do not "look well enough" or frozen to be transferred later if the parents want another child. If the parents do not want to transfer them for a new pregnancy, they are preserved cryogenically (frozen) indefinitely.





Fertilization in test tube







**Embryo** 

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## In vitro fertilization

# IVF with intracytoplasmic sperm injection

Intracytoplasmic sperm injection (ISCI) consists of introducing the sperm cell selected by the technician directly into the ovum. This technique was first used to compensate for the infertility of the father. It runs the risk of transmitting to the child the genetic anomalies responsible for the father's infertility.

Since the success rate of intracytoplasmic sperm injection is better than that of classic IVF, it was used in more than 63% of attempts at IVF in 2008, even when the father did not suffer from infertility. (See Pierre Jouannet, "Peut-on réduire le risque de grossesse multiple après fécondation in vitro?" Bulletin épidémiologique hebdomadaire, June 14, 2001.)

# IVF with donated gametes

Some countries' laws specify that ART must always be carried out with the gametes of at least one prospective parent. In cases in which neither one can provide a gamete (for example, no sperm production and troubles with ovulation), those laws permit the couple to call on an outside donor in order to obtain either sperm or ova.

Unfortunately, the fertility industry in the United States is unregulated. It is even legal for women to sell their eggs.

# IVF with a "surrogate mother"

"Surrogate mothers" are women who are willing to "rent their wombs" when the woman seeking ART is not able to carry a pregnancy to term. The "surrogate mother" carries and brings into the world the couple's child after it has been conceived by IVF and transferred into her uterus. At birth she turns the child over to the couple, usually for payment.

Sometimes the "surrogate mother" becomes pregnant by artificial insemination with the father's sperm; in this case she is also the biological mother of the child.

On average, 17
embryos are
conceived for each
child desired; thus,
16 embryos die.



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In the United States, there is no

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## Legislation

Assisted reproduction is an act that replaces sexual intercourse between a husband and wife with the action of a laboratory technician or doctor as the cause of fertilization and conception. ART is never morally licit. Methods of ART may involve donation or the sale of a woman's eggs, artificial insemination, IVF with embryo transfer, or donation and adoption of embryos created through IVF.

In some places in the world, there are laws in place to regulate the fertility industry. Such regulations limit the number of eggs that may be fertilized and restrict the number of embryos transferred into the womb of the mother to no more than 3 per cycle. Some countries also restrict who may use ART to engender children, restricting its use to heterosexual couples who can prove they are in a long-term, stable relationship.

In the United States, ART is completely unregulated by federal or state law. For example, in 2009, a shocking headline appeared on newspapers

uniform or comprehensive system for the regulation of ART.

across the world: "California Woman Gives Birth to Octuplets." The mother who gave birth to these eight children through the use of IVF was

divorced, already had six young children, was unemployed, and was living on public assistance.

Because IVF involves the creation of more embryos than are transferred, in the United States there are more than 500,000 frozen embryos awaiting their fate in cryopreservation laboratories. These are someone's children who have been recklessly conceived and are awaiting the

generate human embryonic stem cell lines.

Clearly the government should have a compelling interest in protecting human life from this fate.

decision of their parents to be born, to be abandoned and discarded, or

donated for medical research where they will be killed, usually to



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## Frequently asked questions

# Does freezing the embryo affect it?

Freezing "surplus" embryos has risks. Statistical studies show that laboratory mice that had been frozen as embryos had genetic changes.

# Are there physical consequences in a child who is conceived in vitro?

Yes. Besides a higher risk of premature birth, scientific studies reveal a 25% increase in birth defects among children conceived by IVF or intracytoplasmic sperm injection compared with children who are conceived naturally. In particular, anomalies of the cardiovascular, urogenital, and skeletal-muscular systems are observed.



Yes. Children conceived by IVF with donated gametes can experience similar problems as some adopted children. They can be affected by not knowing their biological parents. We all like to know where we came from—to know our parents, who gave us the color of our eyes, our hair, our smile.



With in vitro fertilization, embryos are conceived outside the mother's body. From the moment of fertilization, these embryos are human beings, just like those who are conceived in vivo, even if they are not implanted into the mother's womb. To destroy these embryos is to abort them.



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# Are there consequences for the couple who uses IVF to conceive a child?

Yes. ART is very trying psychologically for the couple because of the intrusion of medical personnel into their intimate relations (for example, a questionnaire about their sex life, the fertilization of the woman's ovum and its transfer, or the insemination of a woman by the doctor instead of her husband). The father finds that he is excluded from the conception of his child, which has become a collaboration between the wife and the practitioner. The parents also suffer psychologically from freezing and destroying some of their embryos.

#### Is it risky for the mother?

Harvesting egg cells can be dangerous. It involves preliminary stimulation of the ovaries and the removal of the ova from her abdominal cavity. The hyper-stimulation of the ovaries can result in hospitalization, development of arterial or venous thrombosis, and on rare occasions, death.

## Isn't IVF the only way to treat infertility?

ART doesn't treat infertility; it tries to work around it. Today, medicine can treat the actual problem. There are techniques that can help couples who think they are sterile to achieve a pregnancy: the Billings Method, which offers a better knowledge of fertility cycles, and the more recent NaPro Technology. an inter-disciplinary approach to procreation (including observation of one's fertility, medical treatments, and surgical interventions). NaPro Technology techniques achieve better rates of success than those of ART. (For more information, see naprotechnology.com.) Finally, the couple can also turn to adoption and offer their home to a child.

# Is IVF connected to embryo research?

Yes. Research on human embryos is a direct result of IVF. Without IVF, it would be impossible to designate "usable" embryos for research.

The large number of embryos in infertility labs are testimony that in the United States, the unregulated practice of IVF is out of hand. This growing supply of "surplus" embryos allows some researchers quite a large supply of "raw materials" that are actually their parents' children and someone's brothers and sisters.



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### **Ethical reflections**

# A child at any cost?

It is not a human right to have a child. Children are not objects to demand or to possess. Infertility is a great burden, but human dignity must never be sacrificed for the goal of possessing a child.

Physicians should seek to cure infertility, not to replace fertility with medical technology that compromises human dignity and results in the devastation of those embryos not chosen.

# **Protecting gametes and procreation from manipulation**

Gametes are unlike any other cells because they are of no use for the life of the body that produced them. The only function of gametes is to conceive a new human being by transmitting the genetic heritage from the father and from the mother.

They should therefore be treated with respect and reserved for the procreation of the couple's children. For that purpose they are irreplaceable, and they should not be manipulated.

ART techniques have brought about a revolution by taking ova out of the woman's body and exposing them to laboratory scrutiny. Gametes are now used for IVF (even for another couple) and for the manipulations that result from this (sperm selection, embryo selection, experimentation on embryos, preimplantation genetic diagnosis, and surrogate motherhood).

These manipulations offend human dignity because they dissociate procreation from sexual union and transform gametes into laboratory material.

"Fertilization outside
the body—making a
child without making
love—and abortion—
the unmaking of a
child—are
incompatible with
natural moral law in
varying degrees."
Jérôme Lejeune



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#### "Wanted children"

The expression "wanted child" emerged during the debates about abortion. It reflects a mindset that regards a child as a human being only if his parents want him to be born. However, what makes him a human being is not the plan that anyone has for him but rather the fact that he is human. Even if the parents did not plan for their child or have changed their plans, the child, whether an embryo or a newborn, is still a human being.

# IVF and embryo selection

Multiple embryos are conceived in each attempt at IVF, and usually 1 to 3 are transferred into the mother's uterus. In the United States, there are no restrictions on how many embryos may be transferred. There are two ways embryos are selected:

- The medical team selects those that seem strong enough to survive. Those that do not have these qualities are destroyed.
- Then, if more than 1 or 2 embryos develop during the pregnancy, the mom is asked to undergo "embryo reduction," in other words, the abortion of 1 or more children to limit the risks of a multiple pregnancy.

Resorting to procreation outside the woman's body promotes the qualitative selection of embryos, which is a form of eugenics. There is no IVF without embryo selection. Some kinds of embryo selection, such as preimplantation genetic diagnosis, are possible only with IVF.

#### "Surplus" embryos

Do you know any surplus adult human beings? Can we say that a human being is superfluous? "Manufacturing" embryos in labs creates an environment where human beings can easily be thought of as products and those not needed for implantation regarded as surplus. An embryo whose parents have no plan for him is disposed of in one of three ways: he is destroyed (which is to kill a human offspring), he is frozen, or he becomes the subject of scientific experiments or research (which amounts to making a human being laboratory material).



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### **Ethical reflections**

# Frozen embryos

In 2010, there were about 500,000 to 600,000 frozen embryos in the United States. These are human beings. Who would ever think of freezing their child until they had time to care for him?

## **Embryos for research**

It is not legitimate to use human embryos for research, because the research exploits and kills those embryos. These are human beings, and no one has the right to dispose of a human being's life, even to save another life. Immanual Kant notes that we are to "act in such a way that you treat humanity as an end, and never merely as a means."

#### **5 parents**

"I am the product of IVF conducted with the sperm of a man, my biological father, and the ovum of a donor, my biological mother. Then I grew inside the body of another woman, my surrogate mother. "Now I live with my 2 adoptive parents. . . . Who are my parents?"

"As of 2003 the estimated number of frozen embryos at IVF clinics in the United States was 400,000.... That number increases annually by about 19,000, which puts estimates in 2010 at between 500,000 and 600,000."

E. Christian Brugger





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## **Testimony**

# "I constantly think about the frozen embryos..."

"I'm the mom of a little 3-month-old girl who was conceived by IVF, and I think constantly about the 8 other frozen embryos. Since we, the parents, have no plans for future pregnancies, and since I cannot bring myself to destroy them, I do not know what to do. . . . The medical team that enabled us to realize our dream is not there for all these questions."

Anne

Quoted on the blog bioethique.catholique.fr, translated from the French.





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## What is preimplantation genetic diagnosis?

Preimplantation genetic diagnosis is a technique for selecting embryos that is used for fertile couples who are concerned about a possible genetic illness.

The goal is to obtain, after in vitro fertilization, the birth of a baby who is not affected by that illness or who has a desired genetic trait.

After creating several embryos, technicians choose those that will be implanted in the mother's uterus. The embryos who are carriers of illness or those who do not have a desired genetic trait are destroyed.



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### Method

"Chromosomal racism is horrible, just like all other forms of racism." Jérôme Lejeune

#### 1 IVF

#### 2 Analysis

Selection

Through IVF, several embryos are created and allowed to develop to the 8-cell stage. One or 2 cells are taken from each embryo.

These cells are then analyzed to determine if the embryo is a carrier of the illness being investigated. This is called an embryo biopsy.

Those embryos not affected by the anomaly being screened are then transferred (implanted) by the technicians into the uterus. If the other embryos are healthy, they are frozen; those who do not meet the criteria are destroyed or used for research.

The destruction of a human embryo, whether in vitro or in vivo, is an abortion.

#### "Designer babies" and "savior siblings"

The term "designer baby" has been used to indicate the possibility of parents using preimplantation genetic diagnosis to select a baby for his physical traits like sex or eye color. In some cases, an embryo may be selected by preimplantation genetic diagnosis to treat his older brother or sister who is afflicted by a serious genetic disorder. In order for the procedure to succeed, the embryo has to meet 2 criteria: he must not be a carrier of the disorder and he must be compatible with his sick brother or sister for a future transplant. Preimplantation genetic diagnosis is the technique that makes this twofold triage possible. Many embryos must be created for the birth of one designer baby. The first "savior sibling," Adam Nash, was born in the United States in 2000 to attempt to cure his sister from Fanconi Anemia.



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## Legislation



Double preimplantation genetic diagnosis to produce a "designer baby" is a doubly eugenic technique. And there are other ways of treating the pathologies for which it is utilized.

Legislation concerning "designer babies" varies among countries. For example,

United Kingdom laws say:

- Parents can only use sex selection if there is a big risk that a genderrelated genetic disorder can be passed on to the baby.
- Preimplantation genetic diagnosis (PGD) is currently legal.
- At the moment, it is illegal to genetically engineer humans, but it is legal to genetically engineer mice, cows, pigs, sheep, and goats.

The U.S. is more lax regarding sex selection and PGD; however, it is still illegal to genetically engineer humans. ("Designer Babies: Legal vs. Illegal," https://sites.google.com/a/gatewayhigh.net/designer-babies2/3-legal-vs-illegal.)

Shannon Brownlee describes the FDA regulations that have been established concerning genetically modified embryos:

Since 1998, the Food and Drug Administration (FDA) has argued that genetically manipulated embryos are a "biological product" and therefore subject to regulation, just like medical devices and drugs. But because of a quirk in federal law, the FDA's authority in this sphere is far from certain. With millions of American couples unable to conceive, doctors and embryologists found a lucrative market for the end products of their work, which could legally continue so long as it involved no federal funds. The fertility industry's self-promotion has gone largely unchallenged, either by the media or the scientific community. ("Designer Babies: Human Cloning Is a Long Way Off, But Bioengineered Kids Are Already Here," Washington Monthly, March 2002.)



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### Frequently asked questions

# Does preimplantation genetic diagnosis cure a child?

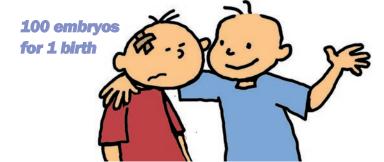
No. Preimplantation genetic diagnosis neither treats nor cures. The purpose of preimplantation genetic diagnosis is to identify genetic illnesses in an embryo created through IVF so that technicians can select from among several embryos only those that are free of genetic defects. Those embryos with illnesses will be killed.

# Doesn't preimplantation genetic diagnosis prevent abortion?

No. The practice of preimplantation genetic diagnosis fosters the development of a mentality of selection and elimination. The purpose of preimplantation genetic diagnosis is to detect sick embryos to destroy them. This is ethically equivalent to an abortion.

#### Isn't preimplantation genetic diagnosis better than late-term abortion?

For the sick babies who are detected, the result is the same: they are killed. Therefore, there is no hierarchy of value. For the parents or the siblings, destroying an embryo in vitro is apparently less upsetting than to destroy the child later during pregnancy, since they are not yet as emotionally attached to the embryonic child as they would be to a several-monthold preborn baby. However, even if they are not aware of it, the moral significance of the act is identical, and they may show some post-abortive symptoms. Ignoring the truth of an action does not free one from its consequences.





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### **Ethical reflections**

# Preimplantation genetic diagnosis and eugenics

Preimplantation genetic diagnosis is a technique for early screening of genetic disorders. However, it promotes the elimination of some human beings (embryos) based on their genetic code. Another term for this is eugenics. Professor Jacques Testart, a French pioneer in IVF, said "preimplantation genetic diagnosis is a promise of discreet, consensual, and large-scale eugenics. ... In the future the use of preimplantation genetic diagnosis will expand severely."

"The movie Gattaca (1997) attempted to portray a future society that had turned to biotechnology to produce genetically enhanced children. Children conceived in the natural way were called 'Invalids' and were looked down upon. Some believe that we may be headed toward Gattaca—a world where 'most children will be conceived in IVF clinics' and selecting the health traits of children will be encouraged by insurance companies and the government to control health care costs."

Bruce Goldmar

# Toward the creation of a "superman"?

In proposing that parents who are not sterile should have recourse to IVF in order to select their child based on genetic criteria, preimplantation genetic diagnosis plays into the hands of transhumanism (or posthumanism). The transhumanist ideology, which originated in the United States in the 1990s, maintains that science and technology can improve the physical and mental characteristics of man and claims that a new species is appearing.

The "techno-prophet" Raymond Kurzweil rejects "all sorts of checks, limits, and prohibitions which, in the name of prudence or ethics, would prevent man from going 'further.' Those who decide to remain human and refuse to improve themselves will be a sub-species."

# Making a "designer baby"

The suffering of parents who face their child's illness is understandable. But is it ethical to create one child to save another? How many embryos will they conceive and eliminate so that just one can live? Even if a "designer baby" got a lot of love from his parents, he would be regarded as an object because of the act by which he was brought to life. He is chosen for what he will offer to a sick person.

How would a child react when he realizes that he was conceived as a medication for his older sibling? And how would he react if he were not "capable" of curing his older brother or sister? How would the parents see this child who was not able to save the older sibling, despite all their efforts? How would an older sibling feel, knowing that dozens of embryos were killed because they could not serve as his medication?



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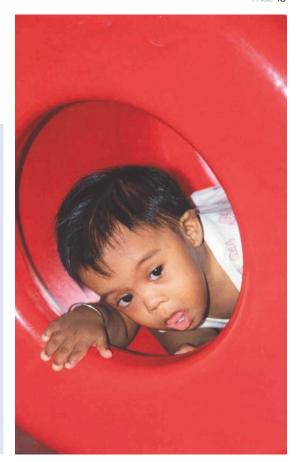
### **Testimonies**

"Preimplantation genetic diagnosis is the means by which eugenics will be able to reach its goals."

Jacques Testart, technological "father" of the first French test-tube baby

"Within the next 10 or 20 years, we will be able to screen every human embryo for all numerical chromosomal abnormalities as well as for many genetic disorders. In the near future it will be possible to determine individual predispositions for cardiovascular illnesses, all types of cancers, and infectious diseases. In the distant future we should be able to identify various genetic traits such as height, baldness, obesity, hair and skin color, and even IQ. Thus, little by little, the ultimate goal of PGD could very well be to normalize the species."

Jacques Cohen, pioneer in human procreation and head of an American laboratory (C. Brenner and J. Cohen, "The Genetic Revolution in Artificial Reproduction: A View of the Future," *Human Reproduction*, December 2000)





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Stem cells are immature, undifferentiated cells that are capable of developing into many types of cells, which make up different tissues in the adult organism. They are "mother cells" obtained and cultivated for the research and treatment of some illnesses.

There are several kinds of stem cells: adult, umbilical, placental, fetal, induced pluripotent, and embryonic. These cells are leading to interesting therapeutic results for some diseases. Of these types listed, only the use of human embryonic stem cells is immoral, because they are obtained by destroying human embryos. The use of fetal cells may also be problematic if obtained through direct abortion.



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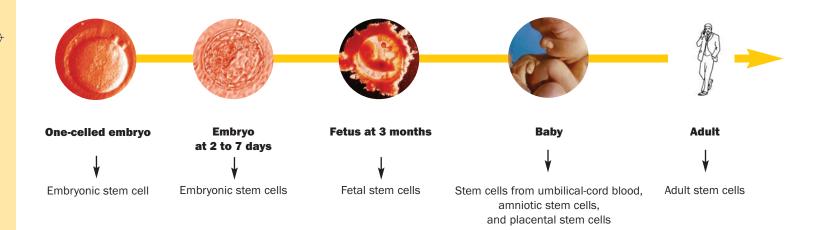
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# Types of human stem cells and their relation to human development





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### Sources of stem cells

#### 3 types of stem cells

#### 1. Totipotent stem cells:

These, from the cells of an embryo up to the *morula* stage, are capable of generating all types of the organism's cells, including the placenta.

#### 2. Pluripotent stem cells:

These are capable of generating all types of the organism's cells, except the placenta.

#### 3. Multipotent stem cells:

These are capable of generating a large number of cells but not all.

## Where do stem cells come from?

**Adult stem cells** are extracted from adults and children (from the skin, muscles, blood, bone marrow, fat, etc.).

**Umbilical stem cells** come from umbilical-cord blood.

**Amniotic and placental stem cells** come from the amniotic fluid and placenta.

**Fetal stem cells** come from aborted fetuses and from miscarriages.

## Where do pluripotent stem cells come from?

**Embryonic stem cells** are extracted from so-called surplus embryos conceived through assisted reproductive technologies and then abandoned for use in research. The frozen embryos are thawed and allowed to develop for 6 to 7 days, to the blastocyst stage. They are then destroyed so that their cells can be extracted.

Induced pluripotent stem cells come from an adult's body (from the skin for example), are deprogrammed and then reprogrammed to become undifferentiated again. Then they can be encouraged to develop into many types of tissue. Their revolutionary discovery by Professor Shinya Yamanaka in 2006 allows researchers to obtain pluripotent stem cells without destroying human embryos.





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#### **Stem cell use**

#### **Cellular therapy**

Cellular therapy is cell grafts or implants aimed at restoring the function of a tissue or an organ when it is impaired. These therapies have benefited from recent scientific advances with stem cells.

Adult stem cells are already being used for the treatment of blood diseases (forms of leukemia) to repair wounds and burns, to repair tendons and to engineer tissues (reconstituted trachea). Some adult stem cells, especially from umbilical cord blood, make it possible to restore cells in the walls of blood vessels. Some are now being evaluated for the treatment of cerebral infantile palsy (infant cerebral motor infirmity), Krabbe's disease, and other conditions.

Although these therapies have benefited from advances with stem cells and hold promise for regenerative medicine (the reconstitution of organs), stem cells will not cure all diseases.

#### Research

Human embryonic stem cells and induced pluripotent stem cells are being used to treat patients in clinical trials. They serve to model illnesses and to screen molecules, useful in pharmaceutical research.

Recent studies show that induced pluripotent stem cells could also produce therapeutic results (for example, successful repair of a myocardial lesion in a mouse).



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# Pros and cons of embryonic stem cells and induced pluripotent stem cells

#### **Embryonic stem cells Induced pluripotent stem cells** Same capacities for proliferation and differentiation Cause cancerous tumors So far, no approved clinical application + Of interest for molecular screening and modeling diseases The patient's immune system rejects them, Not a problem if they are because they are from somebody else's body the patient's own cells Pathological models limited + Produce pathological models directly based on the patient's cells to genetic diseases You have to destroy No ethical problem for use human embryos to get them



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## Legislation



The argument in the United States is over *federal funding* of embryonic stem cell research. Privately funded embryonic stem cell research has been legal all along.

The issue of federal funding for human embryonic stem cell research has long been a point of contention in the United States.

On August 9, 2001, President George W. Bush enacted a ban on federal spending for the purpose of deriving new embryonic stem cells from fertilized embryos. The Center for Media and Democracy notes,

He argued that performing research on embryos is destroying human life and should therefore be avoided. Both the 109th and 110th Congresses passed bills overturning the ban, but both were vetoed by Bush. During the 109th Congress, both houses also passed and Bush signed a bill banning the creation of human fetuses with the sole purpose of destroying them and harvesting their body parts. The Senate also passed a bill encouraging research into the creation of stem cell lines without destroying human embryos. ("U.S. Federal Stem Cell Legislation," July 19, 2007, www.sourcewatch.org, http://www.sourcewatch.org/index.php?title=U.S.\_federal\_stem\_cell\_legislation.)

These policies were revoked in 2009 by the Obama Administration. According to the Stem Cell Information website of the National Institutes of Health,

On March 9, 2009, President Barack Obama issued Executive Order (EO) 13505, entitled Removing Barriers to Responsible Scientific Research Involving Human Stem Cells. The March 9, 2009 EO changes the way National Institutes of Health (NIH) can support and conduct human stem

cell research. The HHS Secretary, through the NIH Director, is required to review existing NIH and other widely recognized guidelines on human stem cell research and issue new NIH guidance within 120 days of the date of the EO. The National Institutes of Health Guidelines on Human Stem Cell Research were published on July 7, 2009. ("Federal Policy," November 14, 2011, http://stemcells.nih.gov/policy/ Pages/Default.aspx.)

Obama's Executive Order 1355 revoked Bush's August 9, 2001 ban on federal spending for deriving new embryonic stem cells from fertilized embryos, and also revoked Bush's Executive Order 13435. According to Steven Ertelt from LifeSiteNews.com,

President Bush put that order in place in June 2007 when he vetoed a Congressional measure that would have required embryonic stem cell research funding. Instead of signing the bill, President Bush issued an executive order to press for more research into ways of obtaining embryonic stem cells without harming human life. The order was intended to ultimately fund research into "alternatives" to destructive embryonic stem cell research such as altered nuclear transfer (ANT), "regression" (reverting differentiated cells into stem cells), and other methods. ("President Obama Also Kills Bush Executive Order for Adult Stem Cell Research," March 10, 2009, http://www.lifenews.com/2009/03/10/bio-2786/.)



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### Frequently asked questions

#### •• Can we use cord blood?

Yes. Umbilical cord blood is rich in stem cells and very useful as a substitute for bone marrow grafts, especially for children.

According to the Herbert Irving Comprehensive Cancer Center's *The Nuts and Bolts of Bone Marrow Transplants*, "In 1991, more than 7,500 people underwent BMTs [bone marrow transplants] nationwide. Although BMTs now save thousands of lives each year, 70% of those needing a BMT using donor marrow are unable to have one because a suitable bone marrow donor cannot be found."

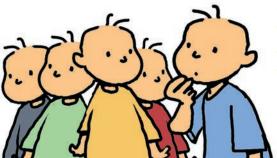
## Can we use animal embryos for research?

Yes. In order to study embryonic development, researchers can use animal embryos; this poses no ethical problem.

The destruction of human embryos is not necessary in order to make scientific progress and improve our knowledge. Professor Shinya Yamanaka made the revolutionary discovery of induced pluripotent stem cells through his work on embryonic mice.



No. Cloning is a manipulation aimed at asexually reproducing a human being who is genetically identical to the original. The nucleus of an ovum is replaced by the nucleus of a somatic cell (not a gamete) of the human being who is to be cloned. In theory, scientists distinguish reproductive cloning (which aims to reproduce a human being who is supposed to be born) from so-called therapeutic cloning (whereby the development of the embryo is stopped at the one week's gestation so as to use his stem cells for research). In reality there is no difference; both are immoral.



Can they make thousands of copies of me for research?



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### **Ethical reflections**

## Using human embryos for research

Research on a human embryo is unethical because it destroys and exploits a human being. It is even more objectionable since there are alternatives, such as research using induced pluripotent stem cells and animal embryos.

#### **Conscientious objection**

In some parts of the world, health care workers are protected from participating in immoral acts, including any act that would cause the death of a human fetus or embryo. In the United States, the Church Amendments, named after former senator Frank Church (D-ID), were enacted in the 1970s to protect health care workers and faith-based hospitals from being required to participate in abortions or sterilizations as a condition for receiving federal funds. These protections are increasingly challenged in the United States, with proposed legislation that undermines the right of conscientious objection.

#### **New slaves**

Now that human embryos are being made available for research, one class of human beings is being exploited to satisfy the needs of other humans.





Whatever the manner of conception, the developing embryo is a living being. If it is a human embryo, it is a human being.

Militants from the Greenpeace movement demonstrating in front of the German parliament against the prospect of patenting human life.



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### **Ethical reflections**

## Research with adult stem cells

Why continue conducting research on human embryos when adult cells are promising and pose no ethical problem? Research on human embryos has not proven to be effective and is unethical since it destroys a young human being. It is good business, and good ethics, to finance the most promising research rather than to slow progress toward the discovery of treatments by focusing on research that shows less promise and is ethically problematic. Thus, research on adult stem cells should be encouraged and promoted.

#### **Cloning**

All countries agree that reproductive cloning is a crime. But some countries accept cloning for research purposes. In so-called therapeutic cloning, an embryo is created only to be destroyed and used as research material. While some like to make a moral distinction between so-called therapeutic cloning and reproductive cloning, there is no true moral distinction. Both are artificial means of creating human life in a laboratory. Therapeutic cloning only compounds the evil by creating life with the purpose of destroying it.

#### **Patenting embryos**

On September 16, 2011, the U.S. Congress passed a ban known as the Weldon Amendment, which prohibits the patenting of genetically engineered human embryos. Tony Perkins, president of the Family Research Council, stated, "While biotechnology offers great hope for treatments and science should be explored, it must always be in the service of humanity, not the other way around. We must never lose sight of the fact that all human life, including human embryos, deserves legal protection" (Steven Ertelt, "Congress Approves Bill Banning Patenting of Human Embryos," *LifeNews.com*, September 15, 2001).



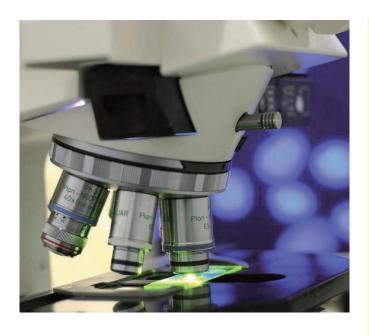
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### **Testimony**

"When I saw the embryo, I suddenly realized there was such a small difference between it and my daughters. I thought, we can't keep destroying embryos for our research. There must be another way."

Shinya Yamanaka

Quoted in Martin Fackler, "Risk Taking Is in His Genes," New York Times, December 11, 2007.

"It is quite remarkable that iPS [induced pluripotent stem] cells are nearly indistinguishable from ES [embryonic stem] cells. They used to be just skin cells or blood cells. But they are now really just like ES cells. They are not just similar. They are almost identical."

Shinya Yamanaka

Quoted in R. Ramachandran, "Reprogrammed Life," interview, *Frontline* 29.9 (May 5–18, 2012).



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### **Euthanasia: What are the stakes?**

Each stage of our life has an irreplaceable value.

The end of life is perhaps the most important.

This chapter concerns the end of life and the question of euthanasia. Caring for a person at the end of life is an opportunity to show him that he has worth, that he deserves respect and attention. Sometimes care at the end of life can mean mitigating his pain and distress by means of palliative care.

> This chapter also discusses organ donations from living or deceased donors.



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### Palliative care versus euthanasia

#### **Palliative care**

"A sick person must always be cared for. Palliative care does not aim to cure but aims to **help the patient** at the end of his or her life. Besides basic care, it includes treatments needed to mitigate suffering and reduce anxiety.

A palliative-care team does everything possible to help the sick person keep his ability to communicate and to keep his autonomy. It provides psychological counseling and offers a reassuring presence by being attentive to the expectations of the sick person and his family.

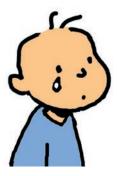
It is essential to relieve all suffering as much as possible. The kinds of care that can be provided at home or in the hospital are:

- Medical care—Alleviating pain by all possible means.
- Psychological care—Providing attention and a caring presence, music, spiritual counseling, and support.
- Physical care—Feeding the patient, keeping the patient clean and comfortable, and providing massages.
- Making sure that the family and friends are welcomed.

Pain relief is part of palliative care. It may require very powerful analgesics, such as morphine and tranquilizers, which sometimes have a secondary effect of involuntarily hastening the death of the patient. In this case, the purpose is not to bring about death but to alleviate the patient's pain (unlike euthanasia, which kills the patient by giving deadly doses of drugs).

#### **Euthanasia**

Euthanasia is always a deliberate action or deliberate omission, the intention of which is to cause the death of the patient. Those involved in euthanasia cause death under the pretense of reducing the patient's suffering. Instead, we must relieve the pain until natural death occurs.



"To die" is a frightening verb. What if this was the last moment of our life in which to love?



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### Legislation



Euthanasia is illegal everywhere in the United States but physician-assisted suicide is illegal only in some states.

Wisconsin Right to Life describes the legal status of assisted suicide in several countries:

#### Where it is legal in the U.S.

Assisted suicide is currently legal in the states of Oregon and Washington, where ballot measures were approved by residents of those states.

Prior to 2000, ballot measures to legalize assisted suicide and euthanasia were defeated in California, Michigan, Washington, and Maine.

A Montana State Supreme Court decision in 2009 failed to declare that assisted suicide is a constitutional right, but left in doubt the legal status of assisted suicide.

In 2012, proponents of assisted suicide gathered enough signatures to put an initiative on the November 2012 ballot to legalize assisted suicide in Massachusetts. The ballot measure was defeated 51%–49%.

From January 1994 to December 2012, there were over 126 legislative proposals in 25 states to legalize assisted suicide and euthanasia. All bills were defeated, tabled, withdrawn or failed due to inaction.

#### Where it is legal in the world

You rarely read about worldwide activity on assisted suicide in news stories or reports. Several countries have legalized or are considering the legalization of assisted suicide. The Netherlands leads the way with

extensive practice of assisted suicide, as well as infanticide and euthanasia.

Other countries where physician-assisted suicide is legal or being considered are:

The Netherlands

Canada

Switzerland

Belgium

United Kingdom

Spain

Australia/New Zealand

Colombia

Luxembourg

For more information, go to http://www.wrtl.org.

Wisconsin Right to Life, 2013,

http://www.wrtl.org/assistedsuicide/assistedsuicide/whereitislegalUS. aspx and

http://www.wrtl.org/assistedsuicide/assistedsuicide/whereitislegalWorld.aspx



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### Frequently asked questions

#### What is therapeutic obstinacy?

The distinction between euthanasia and the discontinuing of disproportionate treatments (therapeutic obstinacy, or "heroic treatment") is essential. Therapeutic obstinacy consists of continuing a burdensome treatment that becomes futile, given the state of the patient. It is always necessary, however, to continue basic care.

The physician must avoid any unreasonable care, for example, a treatment that has proved ineffective or has the sole purpose of artificially prolonging the patient's life. On the other hand, the physician must not discontinue the care that assures that the basic needs of the patient are met (for example, personal hygiene, nutrition and hydration, pain relief, and communication).

#### Isn't outlawing euthanasia 🍧 Is there a difference good enough?

No, because physician-assisted suicide (when a doctor provides the means for a patient to end his or her own life) amounts to the same thing as euthanasia and, like a Trojan horse, is a way of sneaking the murder of the old and ill into mainstream society. In some places where physician-assisted suicide is legal, the elderly fear being killed this way.

## between active euthanasia and passive euthanasia?

There is no reason to make a distinction between active euthanasia and passive euthanasia; it only falsifies the debate.

It makes no difference whether euthanasia is by action or omission, because there is an intention to put an end to the patient's life.



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### **Ethical reflections**

# What good is it to live hooked up to a machine?

Being hooked up to a machine may allow the patient to get beyond immediate danger to survive an accident.

It may also save a patient's life by assisting one of his vital functions that is defective.

When it is no longer useful or when it has no other purpose than to prolong the life of a person who is dying, we may ask if its benefits are proportionate to its burdens.

# What good is it to be alive but unconscious?

What do we know about degrees of unconsciousness? It sometimes happens that people who come out of a coma tell about hearing and understanding what was being said around them even though they could not communicate externally. What do we know about the interior life of a person who is apparently unconscious but whose vital functions are intact? What do we know about the last moments of life? Who are we to judge that these moments are useless? Does anyone have the right to steal them from the patient? And what if they could be the most important moments of a whole life (for example, if they became a time of reconciliation for a broken family)?

# What if the suffering is unbearable?

Well-managed palliative care can alleviate many sufferings. This presupposes a specific training in the treatment of pain and of the sufferings that can accompany the end of life. Therefore what should be promoted is not euthanasia but rather the training of physicians to combat suffering and of other personnel to care for the sick person.





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# What about moral suffering?

Moral suffering often accompanies physical pain and may lead the sick person to ask for euthanasia or to think about suicide. This suffering can be alleviated by sympathetic counseling and appropriate medical treatment.

> "It is quite rare for sick persons who receive care and affection to ask for death."

> > Professor Lucien Israël, member of the American Society of Clinical Oncology and of the Academy of Sciences in New York

#### **Dying with dignity**

Dignity is the unconditional status of a human being. Everyone has dignity because he/she is unique and cannot be replaced by anything or anyone. Every human person has dignity, whatever his or her condition, whether young or old, sick or well, handicapped or able-bodied, conscious or unconscious. Because it is the very essence of a human being, his or her dignity cannot be called into question. Dying with dignity, therefore, implies being respected and not being subjected to euthanasia.

#### **Denying death**

According to a poll conducted by the French magazine BVA/Psychologie, 82% of respondents would prefer to die without realizing it. This sums up a widespread feeling that, instead of "experiencing" your death and confronting it, you should let yourself be surprised by it. This is a symptom of a profound anxiety about death, which is perceived more as an injustice than as a natural process. The acceptance of death by society would more often allow the patient to die at home, surrounded by the affection of his friends and neighbors and the love of his family.



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### **Testimonies**

# Allowing physicians to dispense drugs to assist in killing has an insidious effect on families who support seniors, burdening both the family and the dying:

"The number of patients in Oregon reporting a concern about being a burden on the family increased from 12% in 1998 to 63% in 2000, subsequent to the passage of Oregon's physician-assisted suicide law. Physician-assisted suicide creates in practice a frightening 'duty to die'—frightening because the practice of physician-assisted suicide has been shown to be so imperfect a means of death that in one Dutch study fully 20% of patients given what was considered to be a lethal dose lived for more than three hours, in some cases requiring the physician to intervene with a lethal injection, which would be illegal under the Oregon law."

The Family Research Council, quoted from its April 2005 amicus brief for Gonzales v. Oregon

"Euthanasia and assisted suicide have gone . . . from the unthinkable, to the debatable, to the justifiable, on its way to unexceptional."

Wesley J. Smith, an anti-euthanasia advocate, author, and attorney for the International Task Force on Euthanasia and Assisted Suicide



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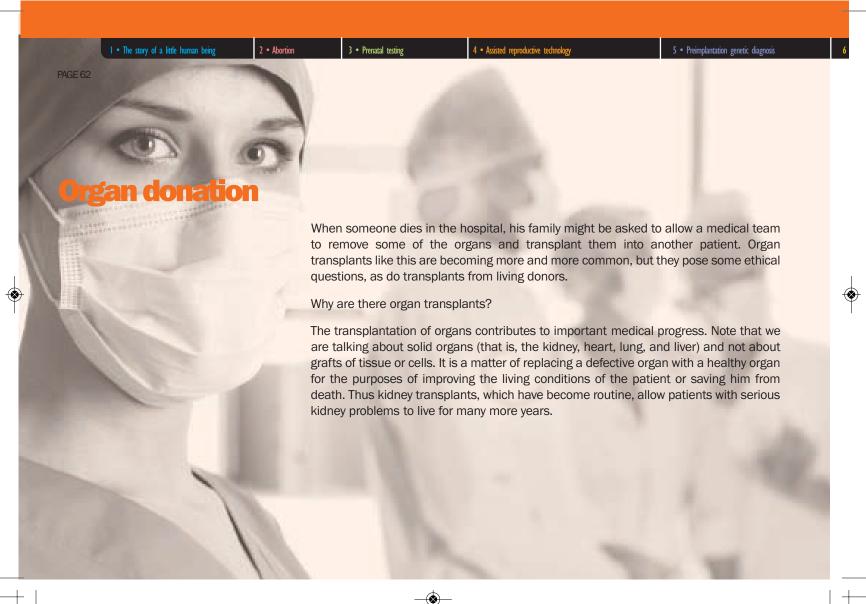
## **Testimony of a man whose father had wanted to die:**

My father suffered a heart attack at the age of 86. He remained significantly weakened and his quality of life was noticeably diminished. Throughout the following 6 to 7 months he often expressed his desire to die. My once-optimistic father was experiencing the four main reasons patients want to die: pain and physical suffering; loss of control over their illness, their lives, and their bodies; the desire to not be a burden; and depression and psychological distress linked to their illness. Owing to his continuous requests to die, his family doctor prescribed antidepressants, which took several months to take effect. Thankfully, his anxiety mostly disappeared as well as his discourse surrounding death and his perception of poisoning the lives of those around him. My family helped him understand that serving his needs was our way to reciprocate for all that he had generously given us throughout his life.

Mercator.net, September 16, 2010







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### **Methods**

## Organs that can be donated

The most common organs that are donated are kidneys and skin. Donations of the heart, liver, lungs, pancreas, and grafts of corneas are less common. On rare occasions, the intestines can be donated.

## **Getting organs** from the dead

Once true death of the patient has been determined using criteria that have been carefully established but before the individual organs have deteriorated, the transplant team may take the organs from the donor's body. Even after death has occurred, the body may be kept "biologically alive" with machines so the organs don't decay before the family can be consulted regarding their wishes.

#### **Determining death**

In 1968, the Harvard Medical School Committee determined that death is no longer defined solely by the definitive loss of the spontaneous activity of the cardiopulmonary system but also by the cessation of brain functions. Thus, since 1968, the total and irreversible destruction of the brain as a whole (and not only of the superior cerebral cortex) allows a physician to certify that the person is indeed dead.

## **Getting organs** from a living donor

Living donors usually give a kidney or part of the liver, and less often, a lobe of a lung. It is a directed gift (that is, the organ is for a relative), and both the donor and the recipient must freely consent to the procedure. The organ is removed only if doing so does not endanger the life of the donor.





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## Legislation

Organ donation and transplantation is one of the most highly regulated areas of health care today. At both the state and federal levels, laws have been put into place to assure that proper consent is received from the donor, and that there is a fair and equitable system in place for allocation, distribution, and transplantation of human organs.

In 1968 the *Uniform Anatomical Gift Act* (UAGA) was passed by the US Congress and provided the legal basis upon which human organs can be donated and transplanted. The UAGA insured that a donor must give free consent to donating their organs before their death.

In 1978 and 1980 legislation was enacted that assured that a universally accepted method of determining death be used to ensure the donor was truly dead before organs are harvested. The *Uniform Determination of Death Act* (1980) reinforced the validity of neurological criteria (so-called "brain death") as an acceptable method along with the irreversible cessation of circulatory or respiratory functions, or so-called "cardiac death".

In 1984 the US Congress established the *Organ Procurement and Transplantation Network* (OPTN) to address the nation's shortage of organs for transplant, and also to improve the process of matching organs to recipients. The Secretary of the U.S. Department of Health and Human Services must approve the policies and bylaws of OPTN.

In 2006, the *Uniform Anatomical Gift Act* (UAGA, 2006) was updated to reinforce the principle of free consent. It also strengthened the power of an individual to elect not to donate their organs while providing the possibility for one close to the deceased to donate their organs if no consent had been given prior to their death.

In the US regulations are in place to assure that organs are donated with the free and informed consent of the donor, and are not sold. International health organizations support these regulations world-wide, but unfortunately some countries are not as willing to enforce regulations to protect donors. In some parts of the world organ traffickers pay individuals small amounts of money for their organs and then sell them at much higher prices to wealthy individuals who wish to bypass the legal processes of their own countries.

For additional information, see http://www.organdonor.gov/legislation





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### Frequently asked questions

#### Is a deep coma the same as death?

No. People in a so-called persistent vegetative state are not dead, because they still have some brain activity. The cardiopulmonary system may even be functioning naturally for some of them. Therefore, the persistent vegetative state must not be confused with the absence of brain activity or with death.

#### **<sup>66</sup>** Are the criteria we use to <sup>66</sup> Is a person dead when determine death valid?

Yes. There has been broad international consensus on using "brain death criteria" to determine death since the criteria were defined in 1968. Regardless, some challenge this definition, asking if the patient is really dead when his organs are removed. They question the validity of these criteria and ask to reopen the debate. Questioning such an important decision is important as new science and understanding become available: however, it is important to note that these criteria for determining death have been re-evaluated and sustained many times since 1968.

# his heart stops beating?

The criterion of "brain death" is generally accepted as legitimate. However, given the growing demand for organs, some people propose using criteria based on the "resuscitation protocol," which states that in the case of cardio-respiratory arrest, if the heartbeat does not start again after 30 minutes of resuscitation efforts, the patient is considered dead. At that point, resuscitation is stopped for 5 minutes, then artificial ventilation and circulation are started again to oxygenate the organs while waiting for the transplant team to remove them. This proposed protocol is problematic. Organs must be removed within 120 minutes after the heartbeat stops, often resulting in a pressured decision by the family to allow the removal of organs, and in ambiguity for the medical personnel who, within a few moments, go from attempts to revive the patient to preparations for removing his organs.



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### **Ethical reflections**

#### **Organ removal**

In order for organ removal to be ethical, there must be free and informed consent on the part of the donor or his family. This requirement applies to both living and deceased donors. In order to remove organs from a cadaver, there must also be moral certainty of death. In the case of organ removal from a living person, the risks must be evaluated before performing the procedure.

#### **Free consent**

Consent can only be valid if it is given in freedom. It may be the case that one feels coerced to "donate" one's organs. Coercion can be the result of familial or moral pressure, or in some cases financial pressure. In some parts of the world the sale of organs from living persons is a profitable business. This is a direct violation of the donor, who is often paid by "brokers" who then sell the organs at much higher prices. This leads to "transplant tourism," which has been condemned by the World Health Organization and professional transplant organizations.

# Respect for the living donor

Despite the generosity of the gesture, there are potential ethical difficulties in organ donation by a living person. The removal of organs is a voluntary mutilation, which is not done for the good of the person himself. This is contrary to the respect due to one's body and to the obligation of physicians always to perform an act for the good of the patient. These rules can be waived, however, for the sake of a higher good (saving the life of another person) provided that this is a voluntary act by the donor and that there is some proportionality between the benefit for the receiver and the risks for the donor. Finally, one must make sure that the donor's consent is free and informed.

# Respect for the deceased donor

Removal of organs violates the integrity of the human body and must not be considered without good purpose. Respect for the integrity of the body continues after death. In fact, violation of a cadaver is illegal. How, then, can this principle be reconciled with the moral good of providing for the needs of the sick through organ transplantation? For organ removal to be ethical, the donor must, during his or her lifetime, make a free choice to donate organs for the generous intention of saving another human life. One's family may make the same choice on behalf of the deceased following death. Living donors, likewise, must make the same decision, free of any moral or financial coercion.





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### **Testimony**

The act of love, which is expressed with the gift of one's own vital organs, is a genuine testament of charity that knows how to look beyond death so that life always wins. The recipient should be aware of the value of this gesture that one receives, of a gift that goes beyond the therapeutic benefit. What they receive is a testament of love, and it should give rise to a response equally generous, and in this way grows the culture of gift and gratitude.

The path that must be followed, until science discovers new and more advanced possible therapies, needs to be that of the formation and diffusion of a culture characterized by solidarity and that opens itself to others without excluding anyone. Organ transplants that are in line with ethic of giving require the commitment of all sides to invest every possible effort in formation and information, so as to increasingly awaken consciences to a problem that directly affects the lives of so many.

It would be necessary, then, to overcome prejudices and misunderstanding, dispel suspicions and fears and substitute them with certainties and guarantees, so as to create in all people an awareness, ever more widespread, of the great gift of life.

Pope Benedict XVI.

Address to participants in the international congress
"A Gift for Life. Considerations on Organ Donation."

November 7, 2008



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### **Gender theory and sexual orientation**

# Hmm...which gender do I want to be?



Gender theory states that the sexual identity of a human being depends on his or her socio-cultural environment and not on his or her genetically determined, biological sex. In other words, it claims that our genetic sexual identity is a less decisive factor in who we are than our skin color, height, or hair color. It purports that our identity as male or female has nothing to do with our genetic reality but is something that is learned within our social environment from an early age.

Some have tried to correlate gender identity to sexual orientation, claiming that there may exist up to six genders: heterosexual male, heterosexual female, gay, lesbian, bisexual, and undifferentiated (or neutral, that is to say, neither male nor female). However, gender (one's internal self-perception of being male or female) and sexual orientation (one's physical or emotional attractions to the same or other sex) are not the same thing.

Both gender theorists and homosexual activists seriously undervalue the biological and social reality of humans and dismiss the psychological conflict created when one's self-perception is in disagreement with one's anatomical reality. The term "gender identity disorder" has been used by psychologists to describe those who believe themselves to be something other than their biological sex. Both gender theorists and homosexual activists assume a reductionist view of the human person, opposing the power of our genetic design and therefore denying real hope to those who suffer from either disorder.



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### **Consequences of gender theory**

#### **New family model**

A family grows from the committed union of a man and a woman. Confusion of sexual roles undermines the family and leads to claims that other forms of "family" have equal dignity. Advocates for the legal recognition of homosexual "marriage," and those who claim that the "right" to have children should be open to homosexual couples through either adoption or the use of assisted reproduction, impose on society an unfounded and opposing social structure.

#### **New social organization**

According to the proponents of both gender theory and homosexuality, society should no longer be based on the differences between man and woman. Instead, they believe that society should consider all forms of sexual expression (that is, heterosexuality, homosexuality, and bisexuality) as being equal.



There is really only one way to create a child: the union of a man and a woman.





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## What makes a child a boy or a girl?

It is impossible to estimate the number of cells in the human body. Some say it could be as many as 70 trillion, but within the core of each somatic cell (cells which are not gametes) there are 23 pairs of chromosomes, including an XX pair for females and an XY pair for males.



44 chromosomes + 2 X = 23 pairs 44 chromosomes + 1 X and 1 Y = 23 pairs

The sperm and the egg are different from any other cell. Each sperm and each egg cell contain half the number of chromosomes as somatic cells. In women, the egg cell contains 22 chromosomes plus an X chromosome, and in men, the sperm cell contains 22 chromosomes plus one X or Y chromosome (since the XY pair that identifies a male divides during the process of division of the sex cells).



22 chromosomes + 1 chromosome X
 22 chromosomes + 1 chromosome X or Y, depending on the sperm that fertilizes the egg.

At the moment of fertilization, the 23 chromosomes from each parent combine, and the genetic heritage of the mother and the father is fused into a new human person. Every newly created life is unique and irreplaceable.

The sex of the child is determined at the moment of conception, from the formation of the first cell. All cells of this new human being throughout his life, will have the same genetic makeup as the first cell created by the fusion of the parents' gametes at fertilization.



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22 chromosomes from the mother
1 chromosome X from the mother
+
22 chromosomes from the father
1 chromosome X from the father
24 chromosomes + 2 X

22 chromosomes from the mother 1 chromosome X from the mother

22 chromosomes from the father 1 chromosome Y from the father

44 chromosomes + 1X and 1Y







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### Frequently asked questions

# Can two persons of the same sex have children?

No. Two people of the same sex cannot engender a child. Through assisted reproductive technology, a donor of the other sex is always necessary, regardless of the technique that is used. A woman may provide an oocyte from her body, or a man may donate sperm, but two women or two men cannot provide the complementary biological parts required for fertilization. The conception of a child always requires two persons of the opposite sex. When assisted reproductive technology is used by same-sex couples, only one can be the biological parent.

# What is the difference between sex and gender?

"Sex" designates the biological reality of the human person (they are male or female), whereas "gender" describes one's self-perception as influenced by culture and the social dimension of masculine and feminine roles.

# What is homosexual parenting?

The term "homosexual parenting" refers to two adults of the same sex functioning as parents and promotes the idea that what matters is *raising* children, not *begetting* them as husband and wife or raising them with the complementary gifts of a man and a woman.

Being engendered through the use of assisted reproductive technology is a gross violation of human dignity. Children deserve to be born out of the loving embrace of their mother and father, and to carry both parents' genetic heritage into the future generations of their family.



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### **Ethical reflections**

#### **Changing sex**

Every human being is genetically a boy or girl. While it is true that family, society, and culture contribute to a child's understanding of what it means to be a man or woman, children usually develop a perception of themselves that is consistent with their biological sex. To develop otherwise is a source of psychological, and often social, suffering.

Proponents of gender theory argue that biological reality is insignificant, that the subjective perception of one's gender is of greater importance than one's anatomy, and that one can change one's sex medically. In fact, there is no way to change one's sex. To try to do so is to mutilate the body and to create a lie within the human person, who may be altered to *look* like the other sex but can never truly be the other sex.

#### **Family models**

Parental love is essential for the healthy formation of children. Fathers and mothers understand, as do their children, that each parent brings a unique perspective of love and devotion to a family. Mothers and fathers together assist children in developing a healthy understanding of their personhood, their relationships, and their sexuality.

In our contemporary world, where we can so easily manipulate nature, we often fail to observe the essential lessons that nature teaches. Society has always acknowledged the relationship of mothers and fathers as the sanctuary in which children are engendered and best brought to adulthood. Parents are complementary in the sexual act that engenders children and also complementary in raising their children.

#### Right to a child

Nobody has a "right" to have a child. A child is not a commodity who comes into the world to satisfy the needs or desires of his parents.

Adoptive families provide the same parental structure and support as those with natural-born children. Recent research has shown that a loving mother and father in a stable relationship are essential to the healthy development of children. (See Mark Regnerus, "How Different Are the Adult Children of Parents Who Have Same-Sex Relationships? Findings from the New Family Structures Study," Social Science Research, 2012.)

The desire of homosexual couples to override the biological constraint on their ability to have children is not a sufficient reason to place children in a same-sex household. Adoption is for children, not for adults. Every child deserves to be nurtured by the complementary love of a mother and a father.



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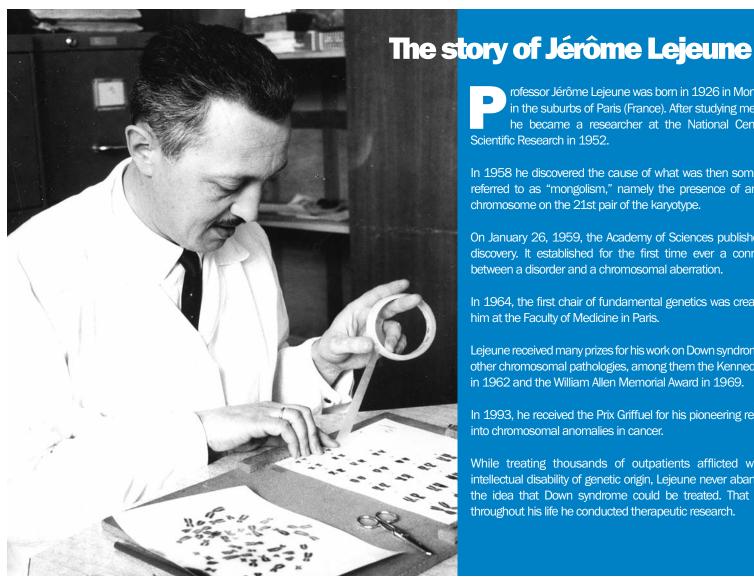
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## **Notes**





rofessor Jérôme Lejeune was born in 1926 in Montrouge in the suburbs of Paris (France). After studying medicine, he became a researcher at the National Center for Scientific Research in 1952.

In 1958 he discovered the cause of what was then sometimes. referred to as "mongolism," namely the presence of an extra chromosome on the 21st pair of the karyotype.

On January 26, 1959, the Academy of Sciences published this discovery. It established for the first time ever a connection between a disorder and a chromosomal aberration.

In 1964, the first chair of fundamental genetics was created for him at the Faculty of Medicine in Paris.

Lejeune received many prizes for his work on Down syndrome and other chromosomal pathologies, among them the Kennedy Prize in 1962 and the William Allen Memorial Award in 1969.

In 1993, he received the Prix Griffuel for his pioneering research into chromosomal anomalies in cancer.

While treating thousands of outpatients afflicted with an intellectual disability of genetic origin, Leieune never abandoned the idea that Down syndrome could be treated. That is why throughout his life he conducted therapeutic research.



For the sake of his patients, he also took a firm pro-life stand immediately when plans were being made to legalize elective abortion and so-called "medically indicated abortion" in the Western world. He gave hundreds of conferences and interviews throughout the world in order to defend human life.

In 1974, he was appointed by Pope Paul VI to the Pontifical Academy of Sciences. In 1982, he was elected to the Académie des Sciences Morales et Politiques in France. In 1994, he became the first President of the Pontifical Academy for Life created by Pope John Paul II. Stricken with cancer, he died on Easter Sunday, April 3, 1994, thirty-three days after his appointment.

During the World Youth Day celebrations in Paris in August 1997, John Paul II traveled to Chalô Saint Mars to pray at the tomb of his friend. The cause for the beatification and canonization of Jérôme Lejeune was initiated in Paris on June 28, 2007.

The Jérôme Lejeune Foundation was created and officially recognized as a non-profit organization in 1996, in order to continue the work of Lejeune. Now with an affiliate in the United States, it has a threefold mission: it designs and funds research projects aimed at developing treatments for Down syndrome and other intellectual disabilities of genetic origin; finances the Institut Jérôme Lejeune, a center for specialized medical and paramedical consultations; and it defends the life and dignity of individuals with genetic intellectual disabilities.

#### www.LejeuneUSA.org

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