Bioethics: Saviour Babies

Student Workbook

Drafting a Bill!

Name: _____

éducaloi

Teaching Legal life Skills

Éducaloi is an independent non-profit organization that explains the law to Quebecers in everyday language.

IMPORTANT NOTICE

The law changes. The information in this guide is up to date to June 2024.

This guide is meant as legal information, not legal advice. If you need advice on a specific situation, consult a lawyer or notary.

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What is a "saviour baby"?

Background

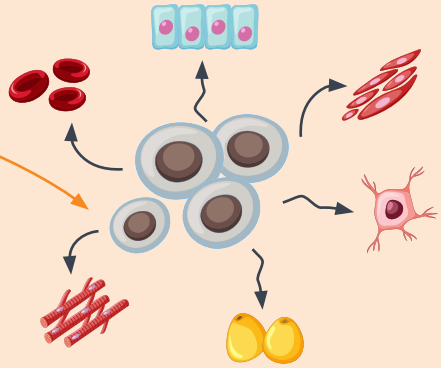
Imagine that you have an illness, and the only cure is a stem cell donation from another person.

Stem cells

Stem cells are parent cells that give rise to all other cells in the human body.

For example, some stem cells lead to the production of red and white blood cells.

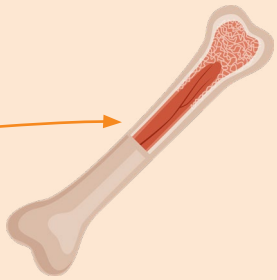
If a disease (such as leukemia) or a treatment (such as chemotherapy) disrupts the development of these stem cells, you may end up having too few red or white blood cells and become extremely weak or die as a result.



Where are stem cells found?

They are found in bone marrow, which is a soft, jelly-like tissue that fills the inside of your bones.

Stem cells are also found in the umbilical cord of newborn babies.



The issue

For a stem cell transplant to work, the donor's cells must match the cells of the person that has an illness. However, **the chances of finding a match are quite low.**

- There's about a one in four chance that a family member is a match.
- There's up to a one in 750,000 chance that a person in the general population is a match.

Possible solution

Your parents could rely on science to create a brother or sister for you whose stem cells are a match and who doesn't have any serious illnesses. A child created for this purpose is referred to as a **saviour baby**.

Saviour baby: A child conceived to cure a person who has an illness.

How is a saviour baby created?

STEP 1 Several eggs are fertilized in a lab.

What is fertilization?

An embryo is created by fertilization, which is the union of an egg and a sperm cell.

Fertilization usually takes place in the mother's uterus. With today's scientific advances, however, fertilization can occur in a laboratory. (This is also known as "in vitro fertilization".)

One of the advantages of fertilization in a lab is that several embryos can be created at the same time.

STEP 2 Scientists select the best embryo.

What is the "best" embryo?

The "best" embryo is one

1. whose stem cells are a good match for the person who has an illness, and
2. that doesn't carry the same disease as this person.

STEP 3 The selected embryo is placed in the mother's uterus.

How does the embryo selected in the lab become a saviour baby?

The "best" embryo is placed in the mother's uterus.

The pregnancy proceeds normally in the mother's body until the baby is born.

After the baby is born, the stem cells from its umbilical cord can be used.

Later, the baby can also donate stem cells from its bone marrow.

Is the creation of saviour babies permitted?

In Quebec?

Embryos can be examined **before** they're implanted in the mother's uterus. This is called "**preimplantation genetic diagnosis**".

In Quebec, preimplantation genetic diagnoses are limited to specific cases. They can't be used to screen embryos for their immunological compatibility in order to create saviour babies.

Preimplantation genetic diagnoses to select a child's sex are not allowed either.

Elsewhere in the world?

Different countries have different rules, and they're changing rapidly.

In 2024, several countries allow embryo selection to create saviour babies, for example: France (total of 9 saviour babies born, based on statistics from January 2021), Belgium (total of 35 saviour babies born, based on statistics from 2013), the United Kingdom, Spain, Portugal and Switzerland (law amended in 2017 following a referendum).

Other countries don't allow embryo selection to create saviour babies, for example: Germany, Austria, Japan, Ireland and Italy.

Drafting a bill!

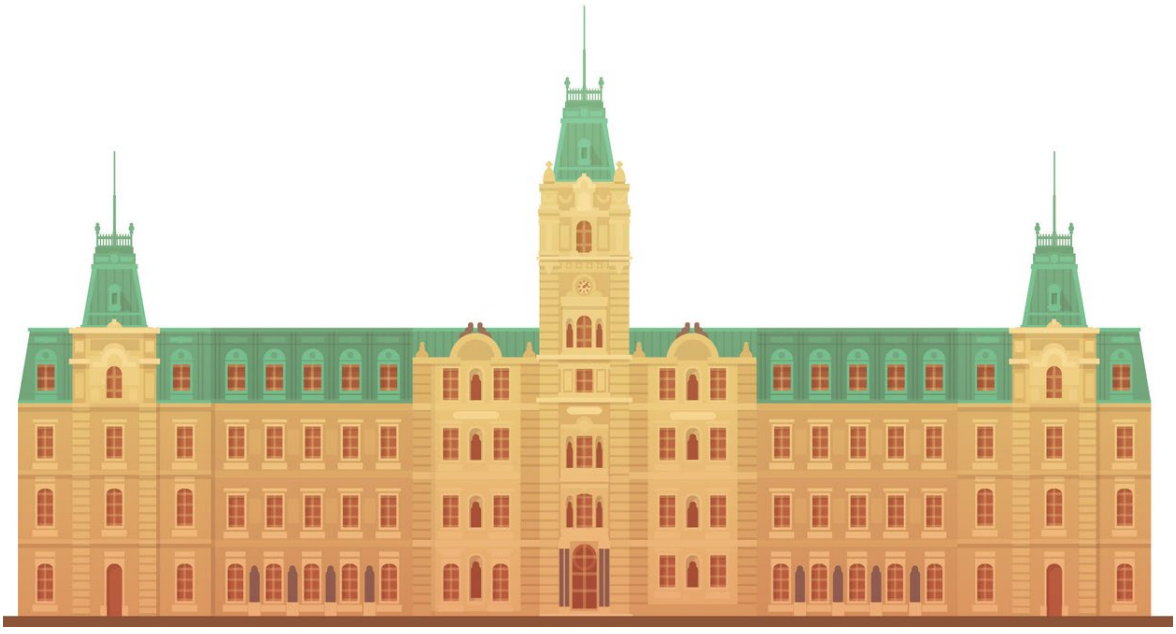
Should the law allow or prohibit the creation of saviour babies? What conditions should apply?

You are a member of the National Assembly of Quebec. You and your colleagues must decide how the law should regulate the issue of saviour babies.

In this exercise, you will learn about many of the issues surrounding saviour babies.

Then you will draft a bill that reflects your beliefs and present it to the class.

Lastly, the class will vote to decide which clauses of the bill will be included in the official law.



Making your decisions

To draft your bill, you and your colleagues will have to consider important ethical issues.

To do this, you must answer two main questions:

1. **Should the law allow embryo selection?**
2. **Should the law allow organ and tissue donations from a child?**

1. Should the law allow embryo selection?

Embryo selection is required to create saviour babies. Is this acceptable?

To help you answer this question, complete Questionnaire #1.

Food for thought

Some people wonder whether embryo selection for the purpose of making saviour babies should be allowed. Should it only be allowed to cure specific people? Siblings? Family members? Anyone else who needs a cure?

Others believe that embryo selection should be permitted only to prevent the future baby from having certain illnesses, but not to cure another person (even a brother or sister). Should we allow all illnesses to be prevented? Which illnesses should the law help to prevent in the future child?

Finally, others are of the opinion that allowing embryo selection could cause things to get out of hand and lead to "designer babies". Through scientific advances, parents or the government would be able to choose different traits in a future child (for example, their sex, the colour of their eyes or skin, their height as an adult, etc.). Should the law allow embryo selection to make "designer babies"? Do you think there's a risk of things getting out of control?

Questionnaire #1

Which statements reflect your values and opinion? Check "YES" or "NO".

Statements	YES	NO
1. Should the law allow **embryo selection**?		
2. Should the law allow embryo selection... to produce a **saviour baby**?		
To **cure**...		
a. a **child only**		
b. a **child or an adult** (for example, the child's parent has an illness)		
c. a **family member** only		
i. a **close family member only**		
ii. a **close or distant family member**		
d. any **person** regardless of whether they're a family member		
3. Should the law allow embryo selection... to produce a **designer baby**?		
a. To **avoid** an illness or disability at birth...		
i. a **fatal disease** (for example, a disease like leukemia, which reduces a person's life expectancy)		
ii. a **debilitating disease** that isn't fatal (for example, multiple sclerosis)		
iii. a **disease that is not fatal or debilitating** but that **has no cure** (for example, severe acne)		
iv. a **disease that is not fatal or debilitating** but that **can be treated** (for example, a minor vision problem)		
v. a severe **physical or mental disability** (for example, a person born without an arm or having Down syndrome)		
vi. other illness or disability: _____		
b. For **non-medical purposes**...		
i. to increase the child's **physical performance** during adulthood		
ii. to increase the **child's intellectual abilities** during adulthood		
iii. for **aesthetic reasons** (for example, eye and hair colour)		
iv. other non-medical reason: _____		

Additional questions for reflection

1) Would it be fair to live in a world where your destiny is decided for you even before you're born? Why or why not?

2) Does this respect the freedom of every person to make their own decisions? Why or why not?

3) Is it up to the parents (or society) to make decisions based on genetics, or should we leave things to chance instead?

4) If we create smarter children or children who are physically stronger, what potential problems could occur?

5) What are your thoughts on creating physically stronger humans to do all the physical work and letting the smarter people govern?

6) Do you think that creating smarter children would speed up human evolution? Why or why not?

The child's interests aren't always the same as the parents' interests. This is called a **conflict of interest**. For example, it's not because a parent wants their tall child to pursue a career in professional basketball that the child will be interested in doing so.

What is in the best interests of the child? Does it mean having the same chances of living a long and healthy life? To be successful? To be happy? To be a "normal" child? (What does "normal" mean? Who decides what is "normal"?)

How to draft a bill

Write down your ideas in the form of actual sections of a law using the worksheet "Writing a bill!" You can refer to the fictional example below of the Bees Act.

Note: According to the House of Commons of Canada, the practice is to use the expression "clause" until a bill becomes law, after which the expression "section" is used.

Rules to follow when drafting a bill

- Number your clauses as follows: Section 1, Section 2, Section 3, etc.
- Include only one idea per clause.
- Write sentences that everyone will understand.
- Avoid synonyms, which are different words that mean the same thing (for example, "baby", "child", "youth" or "minor" when referring to a "person under 18 years of age".)

Fictitious example of a law

Bees Act

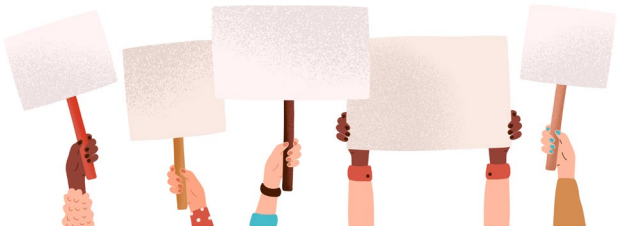
Preamble. Given that bees are important for biodiversity, this law creates rules to protect them from risks caused by humans.

Section 1. No person may spray or dust a fruit tree with a substance that is harmful to bees while the tree is in bloom.

Section 2. Any person who contravenes section 1 must pay a fine of $200 for each fruit tree they have sprayed or dusted.

Procedure for drafting the bill

- Divide into small teams and write several clauses that reflect your beliefs (refer to the questionnaires).
- Present all bills, and choose a bill from one team for the class project.
- Recommend changes to the clauses of the chosen bill. You can also add or remove clauses.
- As a class, vote on the various clauses proposed to create the final bill.



Drafting your bill!

Bill concerning _____

Preamble

Part I – Human embryo selection

Section 1

Section 2

Section 3

Section 4

Section 5

Section 6

Section 7

Section 8

2. Should the law allow organ and tissue donations from a child?

Allowing the creation of saviour babies also means allowing the donation of tissues or organs from a child's body. Is this acceptable? If so, under what conditions?

Food for thought

Some people believe that a saviour baby doesn't really have the option to say no to donating their bone marrow, for example, because the child is too young, because the parents put pressure on them or because it is too great a responsibility since it involves saving a brother or sister who is ill.

If a saviour baby is 4 years old when their sibling needs a stem cell transplant, can the child go against the parents' wishes? What if the child is 14 years old?

Let's begin by learning about some of the organs and tissues that can be donated. Next, confirm your position on various issues by completing Questionnaire #2 on p. 18.

Which organs and tissues should the law allow a child to donate?

Umbilical cord

A few facts

- The umbilical cord is always cut when a baby is born. Afterwards, the umbilical cord is no longer of any use to the baby.
- The umbilical cord doesn't regenerate (the baby will not grow a new umbilical cord).
- The umbilical cord can be frozen for 10 years to preserve the stem cells it contains. After this time, it is discarded.
- The umbilical cord can be used for the baby itself, for the baby's siblings or for any other compatible person.
- Stem cells from the umbilical cord can be used to treat a person weighing up to 50 kg.

Questions to consider: Balancing the different interests

- Is it acceptable to use the umbilical cord?
- What are the disadvantages to the newborn? Are there any benefits? Is it in the baby's interests?
- What are the benefits for the person who has an illness? Is it in their interests?

Bone marrow

A few facts

Surgical procedure

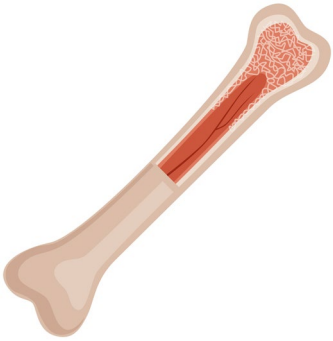
- A bone marrow donation involves extracting bone marrow from inside the donor's bone.
- The donor is under anesthesia and doesn't feel anything.
- The doctors insert a needle into a bone (for example, the tibia, below the knee) and then withdraw some bone marrow.
- Complications during surgery are rare and don't usually lead to serious consequences.

After the procedure

- After waking up from the surgery, the donor may feel pain in the area where the needle was inserted. Other side effects of the procedure include nausea, headache, a sore throat and dizziness for a few days.
- The bone marrow regenerates on its own after the surgery. The donor doesn't have to take any medication.
- The donor simply needs to eat well and rest.
- A donor child can return to school the next day but should avoid sports and physical activity for a week.

Questions to consider: Balancing the different interests

- Is it acceptable to remove bone marrow from a child?
- What are the disadvantages for the donor child? Are there any benefits? Is it in this child's interests?
- What are the benefits for the person who has an illness? Is it in their interests?



Kidney

A few facts

- Most people are born with two kidneys, but we only need one to survive.

Surgical procedure

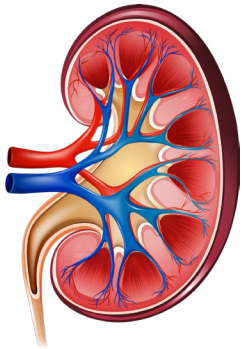
- Donating an organ such as a kidney requires surgery.
- Surgeons make an incision in the patient's abdomen, remove the kidney and stitch up the patient's skin.
- The donor is under "general anesthesia" during the operation and doesn't feel anything. They'll wake up with a scar.
- Complications during surgery are rare, but they can be very serious. Very rarely, the patient doesn't wake up after surgery.

Side effects and risks

- The donor will have to live with only one kidney instead of two. Kidneys do not regenerate.
- If the person leads a healthy lifestyle, stays hydrated, limits their salt intake and doesn't develop a disease that attacks a healthy kidney, they can live well with only one kidney.

Questions to consider: Balancing the different interests

- Is it acceptable to remove a kidney from a child?
- What are the disadvantages for the child donor? Are there any benefits? Is it in the interests of this child?
- What are the benefits for the person who has an illness? Is it in their interests?



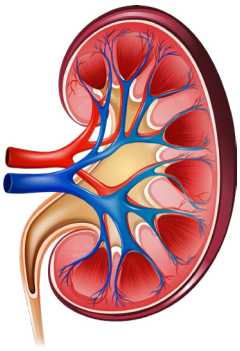
Questionnaire #2

Which statements reflect your values and opinion? Check "YES" or "NO".

Statements	YES	NO
1. Should the law allow **organ and tissue donations from a child**?		
2. Should the law allow **organ and tissue donations from a child** only to save someone's life?		
3. Which organs and tissues can be donated?		
a. **umbilical cord**		
b. **bone marrow**		
c. **a kidney**		
4. **Should the child have a say in the decision?**		
a. Should there be a **minimum age** for a child to donate organs and tissues?		
i. What should the minimum age be? _____		
ii. Should the focus be on the child's **ability to consent** rather than their age (for example, their intellectual capacity or maturity level)?		
b. How can the child's consent or refusal to donate be **confirmed**?		
When a child consents to donating their organs and tissues...		
i. Can they just say "**Yes**" without giving a reason?		
ii. Does the child need **a good reason** to donate an organ or tissue?		
iii. Does the child have to **understand the consequences** or risks of donating an organ or tissue?		
iv. Could a court **refuse to allow a donation even if the child consents**? In what type of situation? _____		
When a child refuses to donate an organ or tissue...		
i. Can they just say "**No**" without giving a reason?		
ii. Does the child need **a good reason** to refuse to donate an organ or tissue?		
iii. Does the child need to **understand the consequences** of their refusal?		
v. Could a court **question a child's refusal**? In what type of situation? _____		

Drafting your bill!

Part II – Consent to organ or tissue donations by a child



Section 9

Section 10

Section 11

Section 12

Section 13

Section 14

Section 15

Section 16

What does the law say about the removal of human tissues and organs?

Right to integrity: A fundamental right

Some rights are so important that they're considered "fundamental" rights (for example, the "right to integrity").

The right to integrity concerns a person's physical and psychological health. It means, for instance, that **a person can't receive medical treatment without their permission**. For example, under normal circumstances, you can't have blood drawn unless you or your parents consent to it.

Consent must be "free and informed"

The authorization ("consent") must be **free** and **informed**.

- "**Free**" means that a person should **not be pressured into making a decision**. For example, family members or the doctor should not try to influence their decision about whether to go ahead with a procedure.
- "**Informed**" means that the person has **all the necessary information** to make the right decision. In a medical context, the person must know all the risks and consequences of a procedure before deciding whether or not to consent to it.

Who decides?

The rules are different depending on whether consent concerns medical treatment or organ or tissue donations.

Authorizing medical treatment: Different rules beginning at age 14

Parents usually make medical decisions for their children under the age of 14.

Beginning at age 14, a teen can decide on their own whether to accept or refuse treatment. However, the rules differ a little depending on whether the care is necessary for their health. For more information, you can refer to our article on different types of health care.

Care necessary for the child's health

A teen **14 years or older doesn't need their parents' permission** to receive care **necessary for their health**. Examples include hospitalization, an abortion, a blood test or cosmetic surgery to treat a burn or malformation.

However, doctors must inform the parents if the child is required to stay in a healthcare institution for over 12 hours.

Treatment not necessary for the child's health

If treatment is **not necessary for their health**, a teen who is 14 years or older can still decide on their own whether to accept or refuse the treatment. An example of this is cosmetic surgery or clinical research.

However, the parents' **authorization** is required if the treatment involves a **serious risk** or if it can have **serious** or **permanent effects**.

To learn more about consent to care, you can visit Éducaloi's website at https://educaloi.qc.ca/en/capsules/consent-to-medical-care-and-the-right-to-refuse-care/.

Donating organs and tissues: Stricter rules apply

Organ and tissue donations are considered a treatment because it involves a medical procedure (for example, a blood donation). Since the donation is primarily made for another person, it's a type of treatment that isn't necessary for the donor's health.

Important! For people under the age of 18, the rules are more strict compared to other types of care not necessary for their health.

A person under the age of 18 who wishes to donate an organ or tissue, such as blood or bone marrow, must do the following:

- Give their written consent.
- Obtain the written consent of their parents.
- Obtain the opinion of an expert.
- Obtain a judge's authorization.

Also, a person under the age of 18 **can refuse** to donate an organ or tissue at any time, regardless of their age or the reason for their refusal. Their refusal must be respected.

If a person is under the age of 18, the law **forbids the removal of an organ or tissue that doesn't regenerate**. For example, they can donate bone marrow or blood, but not a lung, a kidney, etc.

In addition, organs and tissues cannot be removed if it's **harmful** to the donor's health, and donations made in exchange for money aren't permitted.

Self-evaluation of your participation

	Often	Sometimes	Rarely	Never
1. I suggested clauses of the bill to my team.				
2. I suggested that clauses of the class bill be changed, added or removed.				
3. I was open to other people's opinions.				
4. I voted according to my personal beliefs.				

Conclusion of the activity

1) How did you enjoy drafting a bill? What were the positive and/or negative aspects?

2) Do you believe it's important to consider bioethical issues? Explain your answer.

3) Which aspect of saviour babies caused you to reflect the most? Why?

The right to abortion is also a bioethical issue. You can learn more about this topic through the activity "The Evolution of Abortion Rights".