The French Perspective

The law

1994
Civil code: Art. 16-4.
<< No one may infringe upon the integrity of mankind

<< Any eugenic practice which aims at organizing the selection of persons is forbidden.

<< Without prejudice to researches aiming at preventing and treating genetic diseases, there may be no alteration of the genetic characters with a view to changing the descent of a person.

1997 Council of Europe Oviedo Convention, ratified by France in 2012
Art. 13
<< An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.

The French Perspective

Ongoing discussions in academic societies

<< Inserm Ethics Committee

<< French Society of Human Genetics (SFGH)
and French Society of Cell and Gene Therapy (SFTCG)

<< Académie Nationale de Médecine

Human germline editing issues

As discussed at the National Academy of Medicine

1. Potential clinical applications

- Avoiding the transmission of genetic diseases to the child
- Reducing the risks of heritable diseases through elimination or addition of genetic variants
- Nonmedical indications?

In all cases what would be the risks and benefits of HGE compared to other available achievment?

2. Mode of action

- Level of efficiency and safety requested
- How to control safety and efficiency
- Which germ cell or embryo stage could/would be edited?

3. Research

Should it be prohibited or limited?

4. Ethics

- Are the issues different compared to those concerning treatments in reproductive medicine which may impact the genetic, epigenetic or cellular structure and functions in the offspring?
- Should the ethical issues be the same if HGE was done before or after fertilization?

Potential clinical applications

Avoiding the transmission of genetic diseases to the child

<< Preimplantation Genetic Diagnostic (PGD) is not possible

- Dominant homozygoty in one partner (Huntington's disease…)
- Recessive homozygoty in both partners (Cystic fibrosis…)
- Mutations in mt DNA (Leber's hereditary optic neuropathy…)

Potential clinical applications

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<< PGD failure

PGD activity in Necker - A. Béclère centre; Jan1 2015 - Nov 15 2015

119 cycles for genetic diseases; 22 without embryo transfer

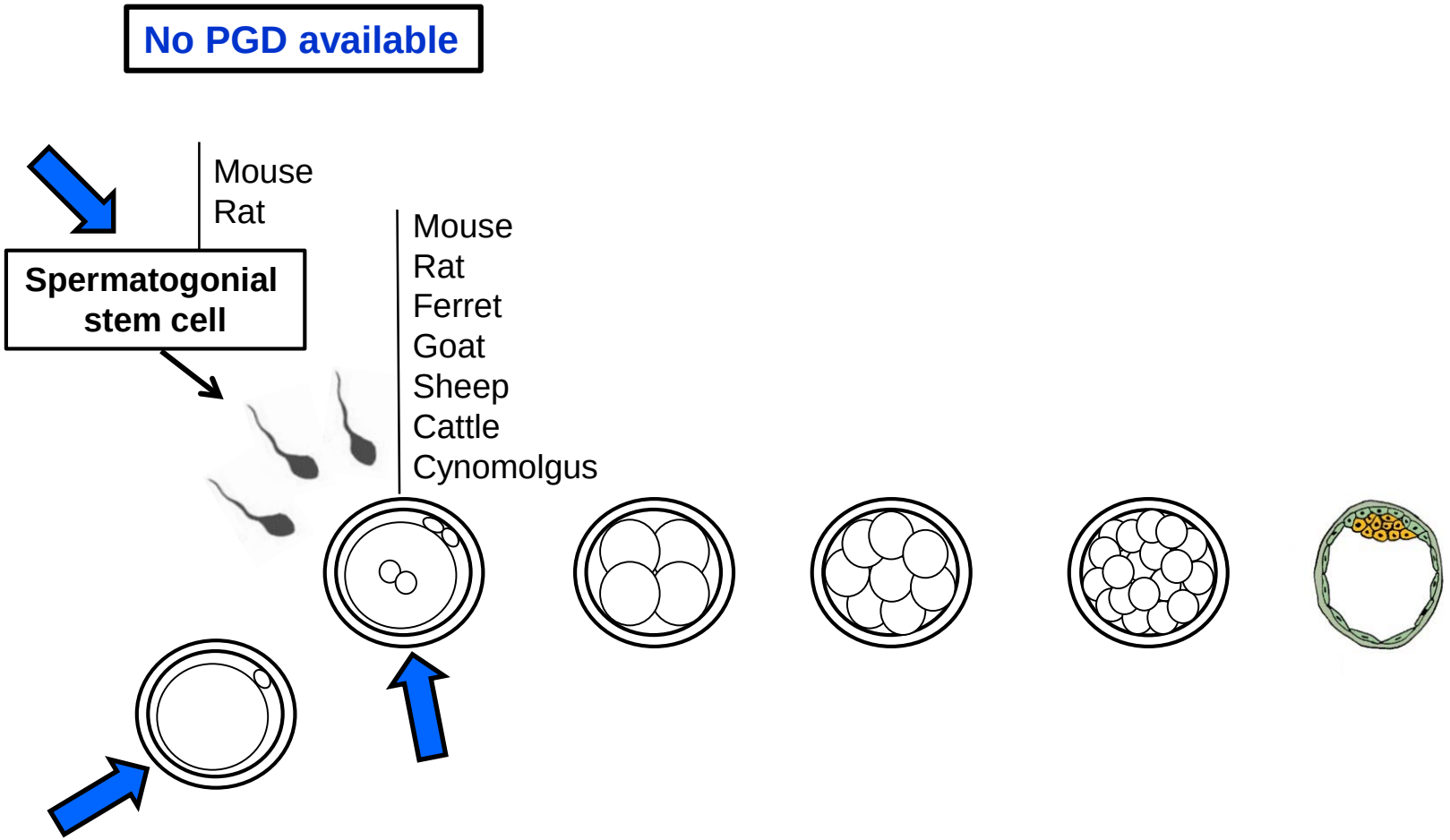
11 autosomal dominant

8 autosomal recessive

2 X linked

1 mt DNA

Which germ cell or embryo stage could be edited?



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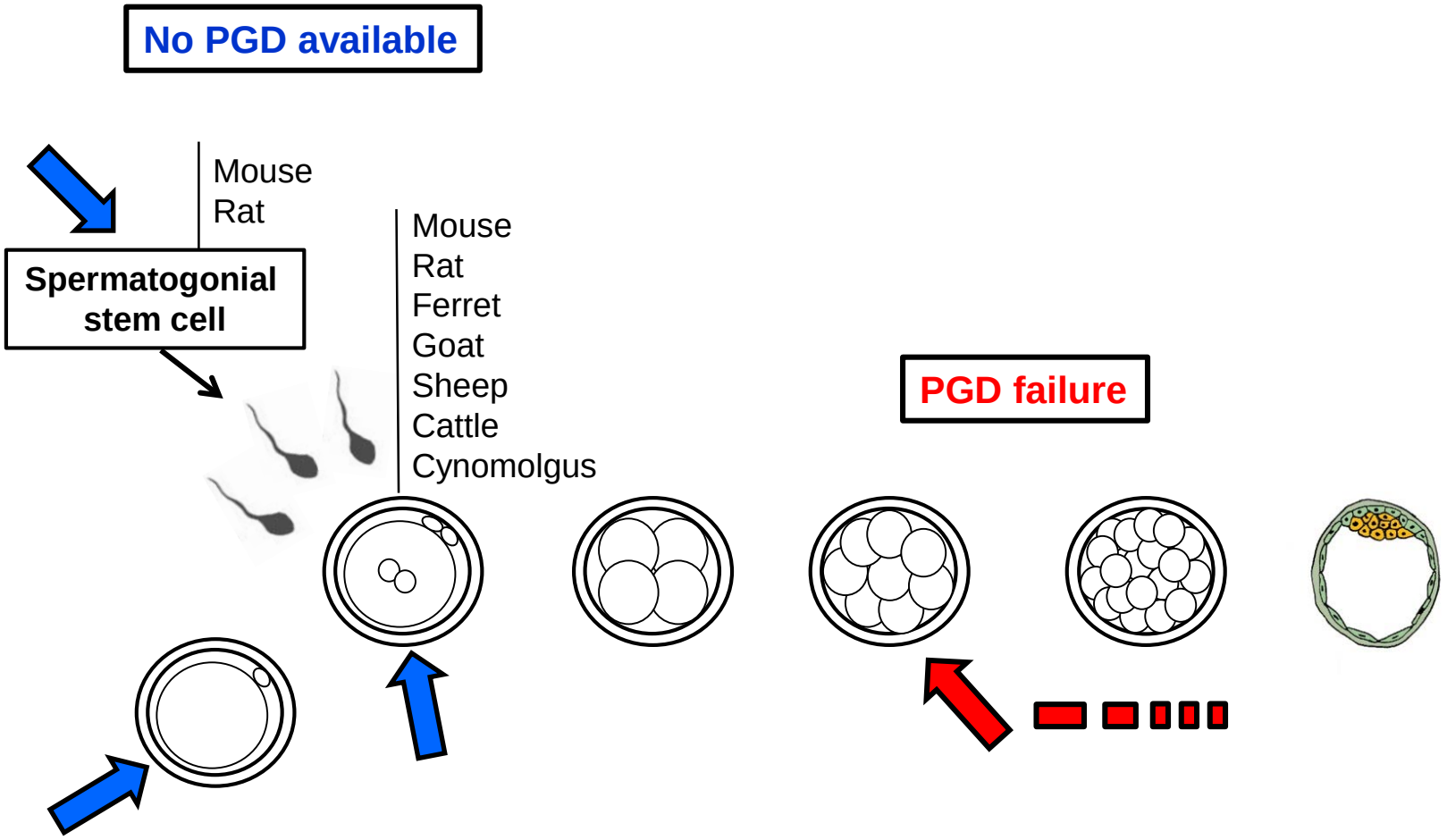
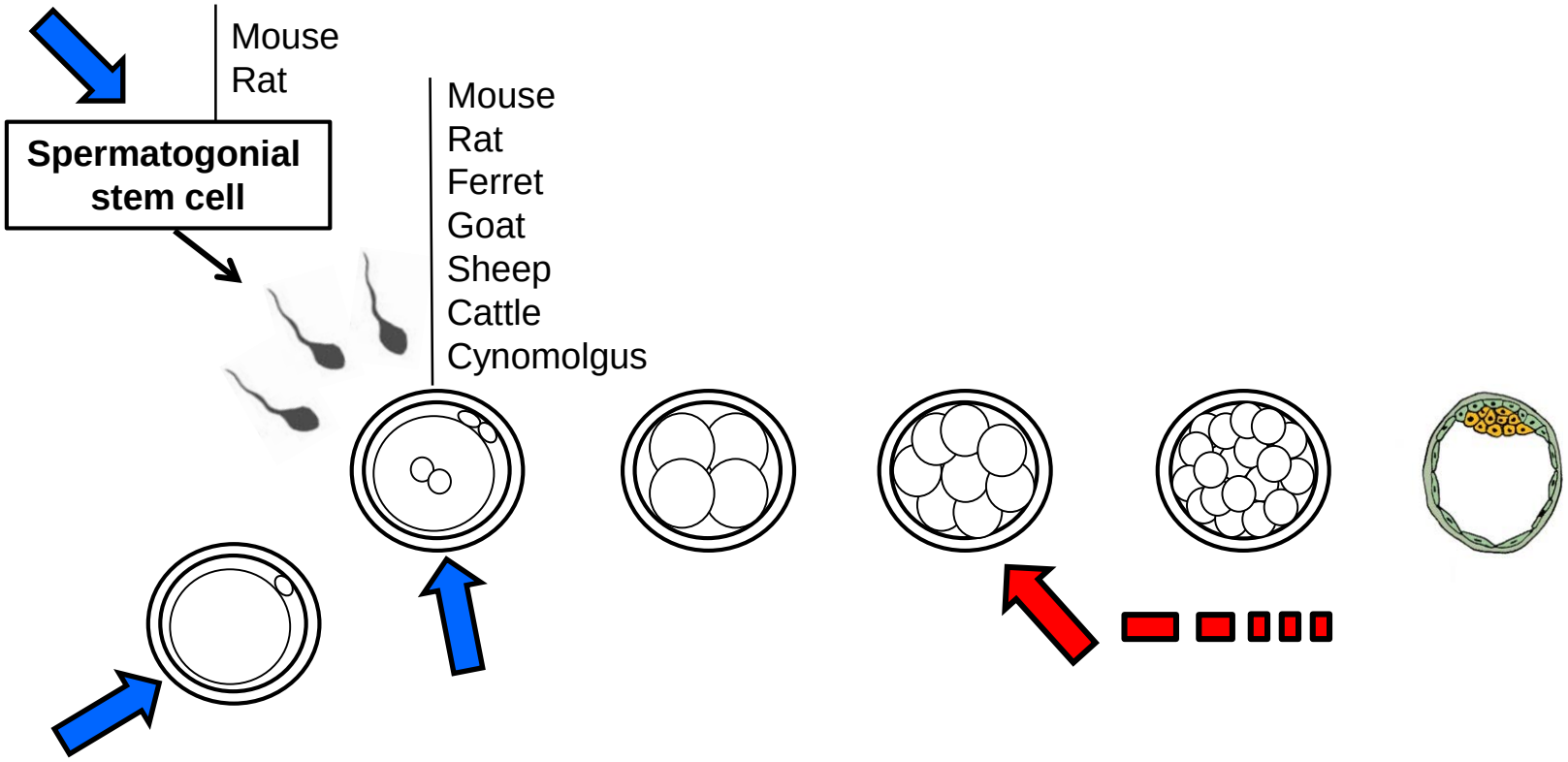


From experimental and somatic editing to clinical germline editing

A paradigm switch



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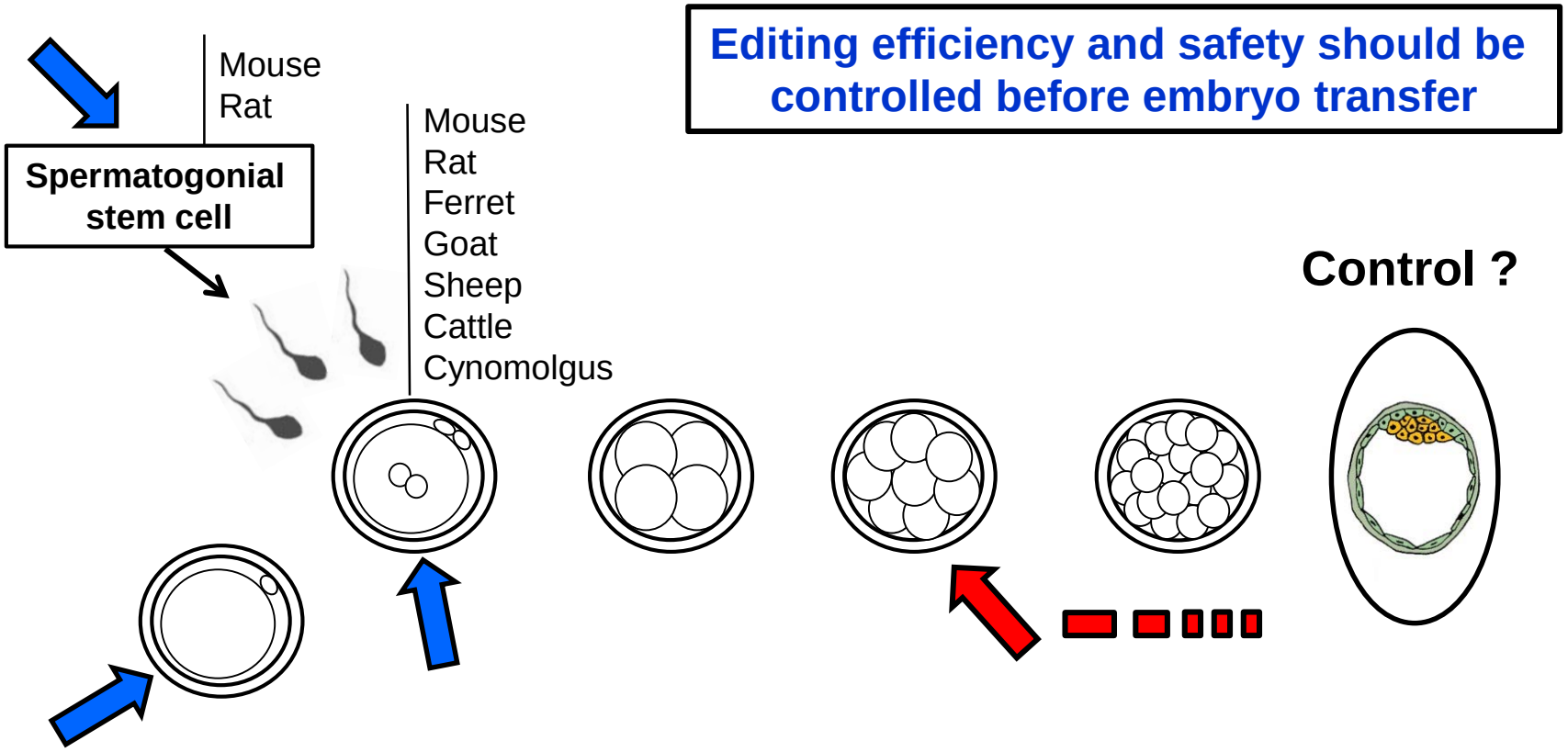

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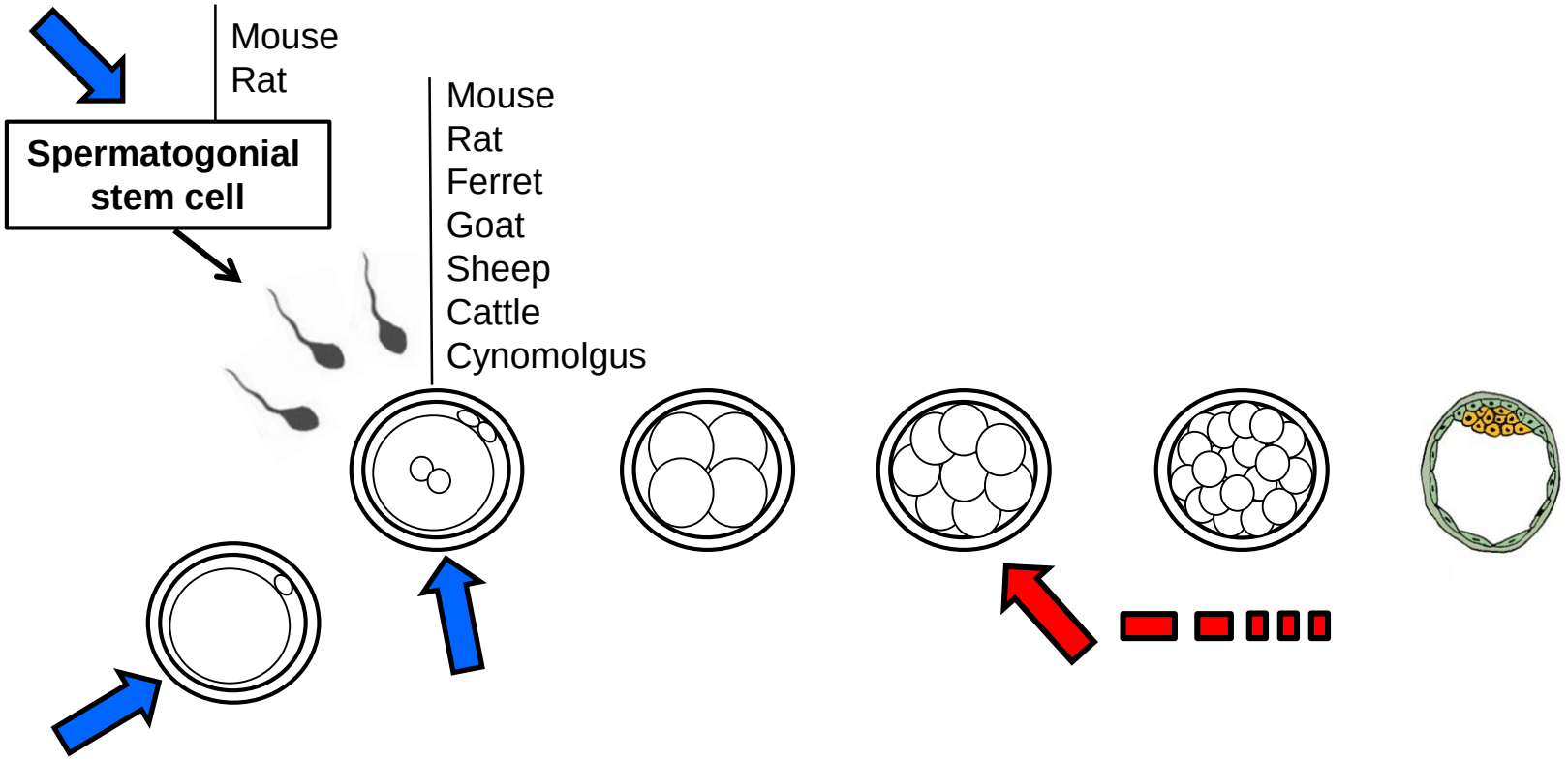
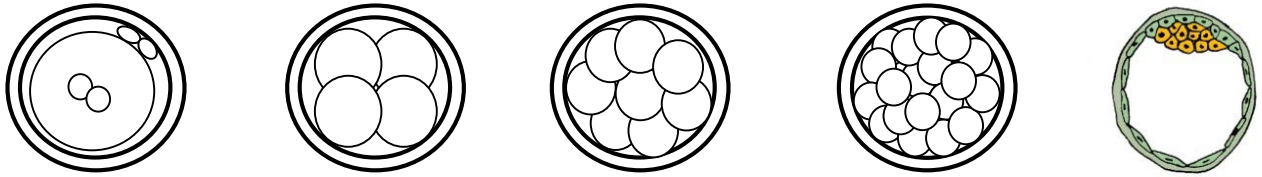


There is a long way to go for research before clinical application

Research

Should not be forbidden.
Will include necessary research on human embryos



Research on embryos is authorized in France

Carrying out research is only allowed on embryos fertilized *in vitro* as part of a medically assisted procreation and only if there is no more parental project

On Dec 31 2013, 19 335 frozen embryos donated for research were stored in the french IVF laboratories (www.agence-biomedecine.fr)

The French Perspective

Since clinical application of human germline genome editing seems impracticable in the short term, there is no reason to change the law.

Research should be allowed and supported when needed. Should the creation of embryos for research be authorized?

The debate is ongoing.