



Facoltà/Istituto	Bioetica	
Ciclo/Livello	Licenza	
Anno del ciclo		Docente
Semestre	2	Prof. Lílian Santos
Orario lezioni		Indirizzo di posta elettronica
Crediti ECTS	1	lilian.santos@upra.org
Ore totali per lo studente	18	Orario di ricevimento
Lingua di insegnamento	Inglese	

DESCRIZIONE GENERALE

After the Human Genome Project, the field of genetics had laid dormant until recently. The surprising advance of CRISPR technology allows scientists and amateurs to edit the DNA of plants, animals, and humans. There is a heated debate about whether we should use this technology not only to correct genetic illnesses, but also to enhance humanity. With the news of the birth of babies in China through CRISPR gene editing of embryos, we have crossed the boundary of genetically modified humans. Would this technology create superior offspring who would be healthier, smarter, and live longer? Could such technology change human nature in a radical and possibly disastrous way? The course will look at the state of the technology and offer some ethical reflections on its use.

LEARNING OUTCOMES (LO)

At the end of the semester, the student will be able to:

- Describe the recent gene editing technology of CRISPR-cas9 in plants, animals, and humans.
- Outline the proposals of human genome editing for somatic and germline cells.
- Examine the situation of the therapy vs enhancement paradigm.
- Indicate the governance attempts to manage human genome editing.
- Analyse the different ethical arguments regarding human gene editing.
- Estimate the challenges and tasks for Bioethics regarding human genome editing.

DISTRIBUZIONE DELL'IMPEGNO PREVISTO PER LO STUDENTE

ATTIVITA' IN AULA	STUDIO/LAVORO AUTONOMO
Lecture and formative assessments (do not affect the final grade): <ul style="list-style-type: none">• Quiz• Conceptual Map• Voting activity• Brainstorming (<i>Think-Pair-Share</i>)	<ul style="list-style-type: none">• Readings (essential bibliography + the chosen reading for the assignment)• Assignment• Documentaries (optional)

MODALITÀ DI VERIFICA

Assignment:

1. Pick one of these readings and analyse the ethical arguments presented.
 - EUROPEAN GROUP ON ETHICS IN SCIENCE AND NEW TECHNOLOGIES, *Opinion on the Ethics of Genome Editing*, Publications Office of the European Union, Brussels 2021, in <http://op.europa.eu/en/web/eu-law-and-publications/publication-detail/-/publication/6d9879f7-8c55-11eb-b85c-01aa75ed71a1> [16-11-2021].
 - NATIONAL ACADEMIES OF SCIENCES, ENGINEERING, AND MEDICINE, *Human Genome Editing: Science, Ethics, and Governance*, The National Academies Press, Washington, D.C. 2017, in <https://doi.org/10.17226/24623> [5-7-2021].
 - NATIONAL ACADEMY OF SCIENCES - NATIONAL ACADEMIES OF MEDICINE - THE ROYAL SOCIETY, *Heritable Human Genome Editing*, The National Academies Press, Washington, D.C. 2020, in <https://doi.org/10.17226/25665> [4-3-2021].

- NUFFIELD COUNCIL ON BIOETHICS, «Genetic Editing: an ethical review», Nuffield Council on Bioethics, 2016, in <https://nuffieldbioethics.org/publications?type=report&year=2016> [19-11-2019].
 - NUFFIELD COUNCIL ON BIOETHICS, *Genome editing and human reproduction: social and ethical issues*, Nuffield Council on Bioethics, London 2018, in <https://www.nuffieldbioethics.org/publications/genome-editing-and-human-reproduction> [20-4-2018].
 - WHO EXPERT ADVISORY COMMITTEE ON DEVELOPING GLOBAL STANDARDS FOR GOVERNANCE AND OVERSIGHT OF HUMAN GENOME EDITING, *Human genome editing: a framework for governance*, WHO, Geneva 2021, in <https://www.who.int/publications/i/item/9789240030060> [13-7-2021].
2. Prepare:
- a. A summary of the chosen reading (max.500 words). 1pt
 - b. An internal and external critique of the ethical arguments proposed by the chosen reading (max.1000 words). 5pt
 - c. Your estimation of the consequences and of the tasks for today's Bioethics considering what is proposed in the chosen reading (max.500 words). 4pt
3. Send your analysis answering the questions at <https://forms.office.com/r/GSfyWQwG1t> by Oct 15, 2024.

CALENDARIO

No.	DATA	ATTIVITÀ
1		<p>Introduction to the course and explanation of the syllabus</p> <p>The recent gene editing technology of CRISPR-cas9 in plants, animals, and humans</p> <ul style="list-style-type: none"> • Gene editing technologies • Uses in plants, animals, and humans <p><i>Instructional methods: Presentation and Documentary Unnatural Selection</i></p>
2		<p>The proposals of human genome editing for somatic and germline cells</p> <ul style="list-style-type: none"> • Somatic, germline, and heritable HGE • He Jiankui and the first CRISPR babies <p><i>Instructional methods: Presentation, Documentary Make People Better, and Quiz</i></p> <p>The situation of the therapy vs enhancement paradigm</p> <ul style="list-style-type: none"> • Problems with definitions • Flaws of therapy vs enhancement paradigm <p><i>Instructional methods: Presentation and Conceptual map</i></p>
3		<p>The governance attempts to manage human genome editing</p> <ul style="list-style-type: none"> • Introduction to Governance • The three International Summits on HGE • National Reports • The Global Policy Landscape • WHO framework for global governance of HGE <p><i>Instructional method: Presentation</i></p>
4		
5		<p>The different ethical arguments regarding human gene editing</p> <ul style="list-style-type: none"> • The Human Gene Editing Debate (Evans) • The predominant values <p><i>Instructional methods: Presentation and Voting with your feet</i></p>
6		
7		<p>The challenges and tasks for Bioethics regarding human genome editing</p> <ul style="list-style-type: none"> • Reasons to try • Tasks for Bioethics <p><i>Instructional methods: Presentation and Brainstorming (Think-Pair-Share)</i></p>
	Oct 15	Submit the assignment

BIBLIOGRAFIA**OBBLIGATORIA**

- BAYLIS, F. - DARNOVSKY, M. - HASSON, K. - KRAHN, T. M., «Human Germline and Heritable Genome Editing: The Global Policy Landscape», *The CRISPR Journal* 3/5 (2020), in <https://www.liebertpub.com/doi/10.1089/crispr.2020.0082> [14-7-2021], 365-377.
- DOUDNA, J. A. - STERNBERG, S. H., *A Crack in Creation: Gene Editing and the Unthinkable Power to Control Evolution*, Houghton Mifflin Harcourt, Boston 2017.
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- KIRKSEY, E., *The Mutant Project: Inside the Global Race to Genetically Modify Humans*, St. Martin's Press, New York 2020.
- SANTOS, L., *Common Themes Between Humanity+ Original Documents on Transhumanism and WHO Documents on the Global Governance of Human Genome Editing. Reflexive Thematic Analysis and Implications for Bioethics.*, Ateneo Pontificio Regina Apostolorum, Rome 2023, in [https://www.academia.edu/104922884/Common Themes Between Humanity Original Documents on Transhumanism and WHO Documents on the Global Governance of Human Genome Editing Reflexive Thematic Analysis and Implications for Bioethics](https://www.academia.edu/104922884/Common_Themes_Between_Humanity_Original_Documents_on_Transhumanism_and_WHO_Documents_on_the_Global_Governance_of_Human_Genome_Editing_Reflexive_Thematic_Analysis_and_Implications_for_Bioethics) [25-7-2023]. Pages 14-22. 72-84. 241-243.
- THE ORGANISING COMMITTEE OF THE THIRD INTERNATIONAL SUMMIT ON HUMAN GENOME EDITING, «Statement from the Organising Committee of the Third International Summit on Human Genome Editing», 2023, in <https://royalsociety.org/science-events-and-lectures/2023/03/2023-human-genome-editing-summit/> [7-3-2023].
- WHO EXPERT ADVISORY COMMITTEE ON DEVELOPING GLOBAL STANDARDS FOR GOVERNANCE AND OVERSIGHT OF HUMAN GENOME EDITING, *Human genome editing: a framework for governance*, WHO, Geneva 2021, in <https://www.who.int/publications/i/item/9789240030060> [13-7-2021].
- , *Human genome editing: position paper*, WHO, Geneva 2021, in <https://www.who.int/publications-detail-redirect/9789240030404> [13-7-2021].
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CONSIGLIATA

- ANDORNO, R. - BAYLIS, F. - DARNOVSKY, M. - DICKENSON, D. - HAKER, H. - HASSON, K. - ET AL., «Geneva Statement on Heritable Human Genome Editing: The Need for Course Correction», *Trends in Biotechnology* 38/4 (2020), in <https://www.sciencedirect.com/science/article/pii/S0167779919303178> [4-3-2021], 351-354.
- BAYLIS, F., *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing*, Harvard University Press, Cambridge 2019.
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- DEUTSCHE AKADEMIE DER NATURFORSCHER LEOPOLDINA, «Ethische und rechtliche Beurteilung des genome editing in der Forschung an humanen Zellen», Saale 2017, in https://www.leopoldina.org/en/publications/detailview/publication/ethical-and-legal-assessment-of-genome-editing-in-research-on-human-cells-2017/?wt_zmc=nl.int.zonaudev.zeit_online_chancen_cb.d_30.03.2017.nl_ref.zeitde.bildtext.link.20170330&cHash=917d02812ecd212da89c9fb5d22f2985 [15-12-2022], 32.
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- EUROPEAN GROUP ON ETHICS IN SCIENCE AND NEW TECHNOLOGIES, *Opinion on the Ethics of Genome Editing*, Publications Office of the European Union, Brussels 2021, in <http://op.europa.eu/en/web/eu-law-and-publications/publication-detail/-/publication/6d9879f7-8c55-11eb-b85c-01aa75ed71a1> [16-11-2021].
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- INTERNATIONAL BIOETHICS COMMITTEE (IBC), «Report of the IBC on updating its reflection on the Human Genome and Human Rights», International Bioethics Committee, Paris 2 October 2015, in <https://unesdoc.unesco.org/ark:/48223/pf0000233258> [14-2-2020], 30.
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Documentaries:

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