



NeuroEpigenEthics

# ERC Starting Grant

Kristien Hens, UA & KUL

# Education

- °1975
- 1997: degree 'licentiaat Germaanse talen Engels-Duits'
- 1997-2007: working in the IT industrie
- 2007: Master in Applied Ethics
- 2010: PhD in Biomedical Sciences (bioethics)
- 2018: PhD in Philosophy

# Academic Career

- 2007-2010: PhD @ KUL (Faculty of Medicine)
- 2011-2014: Postdoc in Maastricht (different country)
- 2014-2017: Postdoc at the University of Antwerp
  - BELSPO Back-to-Belgium grant on epigenetics and maternal responsibility
- 2017-2018: (part time) postdoc @ KUL, 10% ZAP at Ugent, 30% ZAP at Uantwerp, temporary positions

# 2015-2018: Uncertainty

- Uncertainty about job in academia
  - Didn't want to do anything else!
- Applied for jobs, for grants...
  - Problem: interdisciplinary profile (not 'real' philosopher, not 'real' biomedical scientist)
- First ERC attempt: 2014: EPIGENRESPONSIBILITY
  - Got a B, not invited to interview
  - Too soon! Idea fairly original but also more of the same



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# 2017: New Attempt

- 7 years + 3 months after PhD
  - Extension clause (3 sons)



# NeuroEpigenEthics

- Difference with EPIGENRESPONSIBILITY
  - 2014: new subject (epigenetics, autism...)
  - BUT: CV too narrow (many publications but too narrow, not single author philosophical), no methodological innovation, applying old questions to new topics
  - In the mean time: experience with phenomenological research, some publications on epigenetics...

# NeuroEpigenEthics

- NeuroEpigenEthics:
  - Not applying old questions to new topics but questioning the questions themselves
  - Different methodologies: X-Phi, finding a way to investigate opinions of people who do not talk, have intellectual disabilities
  - Interdisciplinary not a problem for the ERC!
  - Craziness not a problem for the ERC!



# NeuroEpigenEthics

*Conceptions of psychiatric conditions as innate or acquired, biological or psychosocial, genetic or environmental influence the ascription of responsibility. Epigenetics strongly indicates that both the social and physical environment affect how genes are expressed, hence suggesting that conceptions, both in folk psychology as in clinical practice, about the nature of some neurodevelopmental disorders as innate and fixed may lack nuance. In NEUROEPIGENETHICS, we investigate how such conceptions influence ascription of responsibility, both capacity responsibility as well as normative responsibility, and analyze what the ethical implications for the child psychiatric clinic are.*



# How to write?

- Start several months in advance and send it to as many people as possible
  - ... who will destroy it
- B1: 5 pages, should be a story (not necessary to spell out methodology)
  - Risks, relevance and novelty
- Convince them that you are the best person to do this, but no need for excessive bragging
- B15: methodology, budget, team, advisory board...
  - Budget
  - Ethics approval
  - Team with junior & senior team members

## Section a: Extended Synopsis of the scientific proposal

*Conceptions of psychiatric conditions as innate or acquired, biological or psychosocial, genetic or environmental influence the ascription of responsibility. Epigenetics strongly indicates that both the social and physical environment affect how genes are expressed, hence suggesting that conceptions, both in folk psychology as in clinical practice, about the nature of some neurodevelopmental disorders as innate and fixed may lack nuance. In NEUROEPIGENETHICS, we investigate how such conceptions influence ascription of responsibility, both capacity responsibility as well as normative responsibility, and analyze what the ethical implications for the child psychiatric clinic are.*

**Capacity responsibility (Hart):**

Responsibility associated with a person's capacity to reason, to foresee harm and to carry out behavior that social norms require from them.

**Normative responsibility**

(Björnsson & Brülde): The requirement to care about what one is responsible for.

**Epigenetics:** Molecular mechanisms that influence how and when genes are expressed, affected by environmental influences.

**Neurodevelopmental disorder:** A disorder of mental function affecting emotion, learning ability, self-control and memory. Unfolding as the individual grows.

**Autism Spectrum Disorder (ASD):**

A neurodevelopmental disorder characterized, in DSM-5, by deficits in social communication and social interaction and restricted, repetitive patterns of behavior, interests or activities.

**Attention Deficit Hyperactivity Disorder (ADHD):**

A neurodevelopmental disorder marked by an ongoing pattern of inattention and/or hyperactivity-impulsivity.

**Tourette Syndrome (TS):** A neurodevelopmental disorder characterized by multiple motor tics and at least one vocal tic.

**Vignette study:** A study in which participants are asked to respond to a hypothetical situation, in order to query their underlying beliefs and values.

**Interpretative Phenomenological Analysis:** An idiographic qualitative research method used for investigating participants experiences, specifically in the light of important life events.

**BACKGROUND**

Although epigenetics is here to stay, and its implications are acknowledged in the philosophy of psychiatry, the practical implications for ethical discussions on the scope and extent of individual and collective normative responsibility have not been adequately addressed.

**Genetics and concepts of human biology**

The concept of genetics as providing a 'blueprint' for human nature is often taken for granted in many discussions on human enhancement in reproductive ethics<sup>1,2</sup>. For example, it has been suggested that human beings could be genetically engineered to mitigate or adapt to changes in the environment and reduce carbon emissions<sup>3</sup>. It has also been suggested that embryo editing techniques, such as CRISPR/Cas9, can eradicate many diseases from humankind<sup>4</sup>. Thus, changing our genes could be a response to the problems we face in relation to the environment and to our health. At the same time, appeals to human nature are used as arguments against the acceptability of certain technologies. For example, Fukuyama has argued that human nature, as 'the sum of the behaviour and characteristics that are typical of the human species, arising from genetic rather than environmental factors' is a guiding principle and that any genetic technologies would unacceptably change human nature<sup>5</sup>. As such, using or subsidizing these technologies is regarded as irresponsible. In the context of autism, the genetic aspect of the condition has been used in arguments against the use of reproductive technologies to prevent the birth of a child with autism, as, it is argued, autism is a neutral genetic variant<sup>6</sup>. Interestingly, it seems that both those who argue in favour of modifying humans to adapt to the environment, or to prevent certain diseases or condition, and those who are against modification humans take one aspect of our biology for granted: that it is to a substantial extent genetically determined. Indeed, often, these arguments are developed against the background of what has been called the *central dogma of genetics*. This central dogma assumes a unidirectional way in which genes define a phenotype (an organism's observable characteristics).

**Neurodevelopmental disorders and responsibility**

In the context of psychiatric disorders, genes influence how certain conditions are viewed. For example, it has been demonstrated that in folk psychology, attributes such as innate versus acquired, genetic versus environmental, psychosocial or biological, are applied to different psychiatric disorders differently<sup>7,8</sup>. Moreover, my PhD student Delphine Jacobs and I have discovered, that the conceptualization of autism as innate and genetic does affect how child psychiatrists and pediatricians view prognosis and capability for improvement. Indeed, clinicians who perceived ASD as an innate and lifelong condition saw their clients' future as more predetermined and less susceptible to change, and their behavior less under their own control than for example in the case of ADHD. Our preliminary findings suggest that a diagnosis of autism is often regarded as an

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## Sub-Project 3: Epigenetics and normative responsibility.

**Research Question:** How should we conceive of normative responsibility in the light of the emerging field of epigenetics?

**Research Objective:** To perform an analysis of societal and scientific aspects of epigenetics and the background theories of responsibilities in order to apply these to the question of responsibility in the context of epigenetics in general.

**Description:** Epigenome-wide analysis and similar technologies demonstrate how the environment changes gene expression. Such environmental influences range from food intake during pregnancy to particulate matter related to pollution<sup>9</sup>. On the one hand, it has been suggested that these influences could be passed on through future generations. On the other hand, it may be more feasible to change gene expression than it is to change the genes themselves. As such, fully appreciating the impact of epigenetics may provide a molecular basis for a systemic and plastic concept of human nature, situating humans firmly as dynamically altering and being altered by the systems in which they live<sup>37</sup>. In this sub-project, we will focus on the question of how epigenetic knowledge about molecular effects, rather than the knowledge of an unexplained causation, affects the discussion. The difference between epigenetic mechanisms and unexplained causation at first sight can be found in two aspects. First, the timeframe in which potentially harmful effects can happen is expanded. Environmental influences may affect future children not only during pregnancy, but also before people even consider having children. Does this increase individual responsibility or is there a heightened collective responsibility to ensure a consistent environment for harmless procreation over a lifetime? The potential *heritability* over generations of epigenetic changes complicates the issue further: should women (and men) change their behaviour if this possibly affects the health of their grandchildren or great-grandchildren? Should this fact be part of policy decisions? Another aspect of epigenetics, which has been demonstrated in cancer treatment, is that epigenetic changes may be *reversible*<sup>70</sup>. Does reversibility relieve people or society of part of their responsibility? Do we invest in restorative strategies rather than preventative strategies, or do we invest in both? Or does the complexity of our biology, as suggested by epigenetics, call for a revision of our concepts of responsibility in their entirety?

**Methodology:** In this part, we will analyse the ethical and philosophical literature on responsibility in depth against the background of findings in epigenetics. We will analyse philosophical approaches to the concept of responsibility, the clash and interaction between individual and collective responsibility and the impact of dynamic conceptions of human beings on concepts of responsibility. We will apply the result of this analysis to the specific context of epigenetics, with special attention to how reversibility, heritability and long term effects of epigenetic influences complicate or inform the discussion on responsibility.

**Risks & Gains:** There is a risk that that epigenetics as a field of study is overhyped, and hence that a project trying to find out how epigenetics influences concepts of responsibility is overstating its relevance. However, in science, epigenetics is generally acknowledged as offering a new and complex outlook on (human and other) biology. Moreover, even if it is not possible to read out new sets of responsibilities directly from the science of epigenetics, it can function as a metaphor of the complexity of human dynamics and interactions, and as such of the complexity of questions regarding responsibility.

**Timeline:** Year 2-3.

**Deliverables:** One conference and a special issue or edited volume on 'Epigenetics, Ethics and Responsibility', covering issues surrounding the ethics of epigenetics in the context of responsibility towards future

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# NEUROEPIGENETHICS



Postdoctoral researcher,  
Interdisciplinary profile  
(psychology, philosophy,  
qualitative research  
methods)



PhD Student I  
Interest in philosophy  
and psychology



PhD Student II  
Interest in philosophy  
and applied ethics



**Kristien Hens, PI**  
**Bio-ethicist, interdisciplinary  
expertise**  
(applied ethics, genetics,  
philosophy, ethics, qualitative  
research methods)

KU LEUVEN

↑ LAURES

 **Centrum voor Ethiek**  
Universiteit Antwerpen

AEN 

Autism Ethics Network *Bringing together the social sciences  
and humanities for a better understanding of autism*



**Daniela Cutas**  
Professor in Ethics, Umea University  
Expertise: family ethics,  
responsibility towards children



**Sander van de Cruys**  
Researcher in experimental psychology  
Expertise: neurodevelopmental  
disorders



**Andreas De Block**  
Professor in Philosophy, KU Leuven  
Expertise: philosophy of psychiatry



**Anna Smajdor**  
Professor in Ethics, Oslo University  
Expertise: epigenetics and  
reproduction, concepts of naturalness

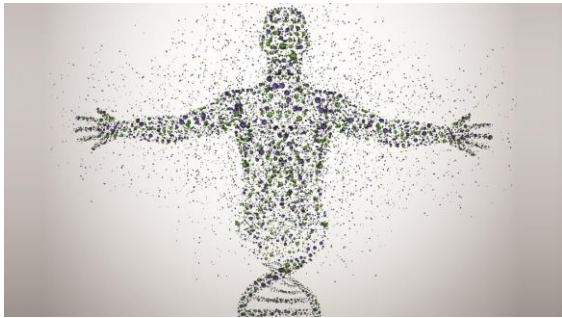


**Jean Steyaert**  
Professor in child psychiatry  
Expertise: neurodevelopmental  
disorders (autism & Tourette  
syndrome) psychiatric genetics

# Interview

- 5 minutes presentation, 15 minutes questions
  - Depends on panel
- Be yourself!
- Don't waste time learning the presentation by heart!
- Do mock interviews!
  - They are horrible, but do it anyway
- Ask people to read your proposal and send you all possible questions
  - Spend a couple of days in advance answering them ON PAPER
- Be enthusiastic about your proposal!

## Epigenetics: Life is experience



Innate  Acquired

Genetic  Environmental

Biological  Psychosocial

➔ Human beings as dynamically linked to environment

➔ Case: neurodevelopmental disorders

1.5 Months later...

*We are pleased to inform you that your proposal has been retained for funding in this call.*



# 1.5 months later...

- Unbelief, euphoria...
- Lots of administrative stuff before it can actually start...
  - Ethics approval, DPO officer,...
- Cold feet
  - Suddenly you have to manage a team
- But also: dream come true!



# Should you do it?

- Look before you leap
  - Investment of time and nerves is great!
  - There is value in incremental research, applied research, valorisation research
- But for me...
  - Appreciation of interdisciplinary research
  - 'non-conventional' CV did not really matter
  - Place for crazy ideas
  - No need for ZAP position in order to apply
  - Possibility to start a research team

# NeuroEpigenEthics

Investigating entanglements of human biology, responsibility and experience

NeuroEpigenEthics aims to investigate how dynamic concepts of human biology influence the ascription of responsibility, specifically in the context of neurodevelopmental disorders. We use a combination of theoretical and empirical methods, with a special focus on the importance of experience stories.