

EARS presents

Adapt the creation



*An exploration
of views and
dilemmas around
gene modification*

Introduction

Cut and paste in someone's DNA. It sounds like science fiction, yet in reality, the future is at our doorstep. Recently, a Chinese doctor caused a lot of controversy about genetically modified babies. With the CRISPR-Cas technique it is possible to change the embryo's genetic structure and make this change final for the entire offspring. Before you know it, we can terminate hereditary diseases. And before you know it, we are talking about 'designerbabies'. With blue eyes, brown hair and inclined to sports. Yes, the technique is still in its infancy and no, it is not safe enough yet. But what if it is, in the near future? What do we think about that?





Dilemmas

People who are carriers of a hereditary disease are faced with a huge dilemma if they have the desire to have children. What if I transmit the disease? At this moment a few medical techniques like prenatal diagnostics and embryo selection are available to ensure that parents are not transmitting their hereditary disease onto their future child. Each technique has its disadvantages.

CRISPR-Cas

A recently developed technique, that due to laws and regulations cannot yet be used by parents, is CRISPR-Cas. To summarize: scientists can meticulously modify DNA with this technique. They can literally cut and paste. This offers the possibility to remove bad genes from a person's DNA. If you would apply this technique on an embryo or even an individual ovum or sperm cell to prevent hereditary diseases, it is a permanent change for the offspring. This is also called germline modification. This seems like a huge opportunity that makes other techniques no longer necessary, but it also raises many questions. Little is known yet about the long-term effects. Additional research and changes in law and regulations are needed before a clinical application will become a possibility.

Economic interest

The CRISPR-Cas technique requires large investments. Fundamental research needs to be funded and the government does this only partially. However, interests are large. Avoiding serious illnesses will majorly decrease costs for health insurance companies and general society. Researchers for this technique will certainly find financiers, such as banks, hedgefunds, etc. Who will eventually invest with risk and perhaps subsequently earn money? The conventional pharmaceutical industry? The government? The hedgefunds? The banks? With the development of patents, a lot of costs and revenues are involved. Where for patients there are health benefits in the long term, economic benefits arise to investors. Law firms, who have to advise about entering upon this market, will benefit from the further development of CRISPR-Cas as well.





Legal Legislation

In its current form, the Dutch laws and regulations regarding this field, the Embryo law, makes further research and clinical applications on germline modification impossible. And though politicians control the final decisions, it is necessarily pressured to continue competitive research and is of commercial importance.

The objections

The technique is not only prohibited, the prohibition relies upon a range of moral, legal, and philosophical considerations which cannot be ignored. For example, think about the term identity (after all, who intervenes in the genetical structure changes the individual's identity), but also the question to which extent a person should be allowed to intervene in nature, or in human creation. To formulate it clearer: does the technique preclude a certain artificiality of human nature? At which then honestly should be mentioned modern life will always be artificial to a certain extent. Where would we stand without modern medicine and such?

CRISPR-Cas before fertilization

Many moral aspects seem to connect strongly with the desire to not to intervene with the life of an embryo. That the CRISPR-Cas-technique is also possible before the fertilization, so only on an ovum and/or sperm cell, seems to be completely out of sight. That fact, however, makes a crucial difference for the discussion.



Social (A)social?

A duty or not to have the right?

The questions around germline modification know many stakeholders. Consider researchers, patients, companies, the government and common citizens. They all defend their own interests. Public research from 'De Kennis van Nu' from 2016 shows that the majority (85,2%) of Dutch citizens is for changing a genetic disorder in their own body. The same research shows that 65,7% of respondents would modify the embryo of their child if they would be personally affected by a transmittable inherited disease. However, when they would personally be healthy, only 29,6% would genetically modify their embryo. When it comes to enhancing the embryo, for example increasing its intelligence, only 15,4% of respondents are positive. There seems to be two sides: parents who find it their personal duty to give their future child the best personal starting position and the parents who believe it is not their right to decide for their child.



Does possibility of choice lead to choice coercion?

New techniques such as CRISPR-Cas lead to new possibilities and new questions. Genetically burdened parents will have the possibility to not burden their future child with the genetically inherited disease. They can break the cycle. Can. Or must? What is the response when parents decide not to participate in the procedure? Would they be judged for this? Would it maybe even influence your possibility to ensure for medical expenses?



Philosophical **Who am I?**

Regarding identity

Within the discussion of germline modification, the term identity plays an important role. What is identity? When is it formed or already present? What determines someone's identity actually? Some people say genes determine your personality. That would imply that to tinker someone's genes, you would tinker one's identity. The question is whether we should want this. Opinions differ. Is someone's identity actually fixed? Or is it something that continuously changes, which would make it impossible to modify regardless.

Identity and culture: two sides of the same story

Who or what a person is strongly depends on cultural conceptions. Is an embryo already a person with an identity? Or are you only a person when you are born? Or maybe even as late as when you are able to talk? Transgenderers clarify that gender isn't necessarily what determines one's identity. Then why stop at genetical structure? In other words: cultural, philosophical, religious, and theological considerations determine the frame in which these questions are dealt with.





Moral & Religious

Cure, prevent, and improve: where is the limit?

It is commonly accepted that we treat the people who are ill. Curing is the central focus within healthcare. Techniques such as prenatal diagnosis and embryo selection are already a step ahead. They are focused on preventing disease. Techniques which used to issue a lot of controversy, are now widely accepted. CRISPR-Cas too is focused on preventing hereditary diseases. It is explicitly not meant to go beyond this: improving. In other words: modification for social reasoning, rather than medical purposes. The description 'designerbabies' then quickly comes to mind. The boundary is in essence always fluid. What now is considered 'improving', can be considered something different in the future. For example, the way that the boundary of the term 'unbearable suffering' has been redefined by euthanasia, taking not only the physical, but also psychological domain into account. Fading and stretching limits always underlie ethical questions. What do we approve and disapprove of? Where do we stop?

Value of life

The value that we assign to life plays a big role in determining our ethical boundaries. Is the life of someone who is ill worth less than that of the life of someone who is healthy? Do we have the ethical command to restore where possible? And with regards to qualifying life: when is a disease severe, and when is in not severe enough?

Religious perspectives

Regarding moral questions, religions can barely commonly agree. The number of perspectives and movements make it impossible to hear the opinion of 'the' Catholic or Protestant or Muslim. Individualization of religion makes researching religious opinions within the context of germline modification very challenging. Nevertheless, PEW Research Center indicated that religious Americans are rather skeptic in relation to germline modification. It is 'meddling with nature'. White Pentecostals are most opposed to this development and atheists are most in favor of it. The Catholic church has explicitly turned against growing embryo's purely for medical purposes. She states that an embryo is perceived as human, starting at the moment of conception, which is why growing of embryo's is unacceptable. The Protestant church in The Netherlands seems to be reluctantly agreeing and opts for reflection.





Conclusion

It is time to acknowledge the possible scenarios, to apply nuances and to enter into dialogue with one another. To recognize that reflection and debate is necessary. Because in the current situation, where scientific progression in combination with a politically hesitant attitude are the dominating factors, a social debate is highly desirable. Many social institutions strongly insist doing so. From the 'Koninklijke Nederlandse Akademie van Wetenschappen' to the European Council. What exactly is germline modification? What questions are being evoked? What should we do with it? Two things are certain: Shutting off from it is not an option. Just as much as carelessly supporting it is not.

Learn more?

<https://ghr.nlm.nih.gov/primer/genomicresearch/genomeediting>

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