

# Young Europeans Science Parliament

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European Parliament/Brussels

## Resolution

The Young Europeans Science Parliament (YESP) took place in the European Parliament in Brussels/Belgium from November 29 to December 1, 2010. 58 students from 29 cities and 17 countries participated in the YESP which is the final event of the 2WAYS project.

In the course of the YESP, the students were divided into four committees. Each committee discussed one particular predefined question related to the general topic of life science. They had the possibility to spare with a specific expert of their committee. The topics of these committees and their attendant experts are:

**Committee 1: Use of embryonic stem cells: Blessing or Curse?**

What are the opportunities and threats of this technology? To what extent should embryonic stem cells be used?

*Prof. Dr. Hans-Georg Kuhn, Institute for Neuroscience and Physiology, University of Gothenburg (Sweden)*

**Committee 2: Using the results from genetic tests: what are the consequences for society?**

Genetic tests can lead to a better treatment of diseases, but who should get hold of the results? Should insurance companies or employers get access to the information? How can abuse be avoided? How can a legal environment be created that secures the privacy of the results?

*Gadi Glaser (PhD), Faculty of Medicine, The Hebrew University of Jerusalem (Israel)*

**Committee 3: When genes are responsible for an aggressive behaviour?**

Brain research has discovered that genes control processes in our brain that might lead to an aggressive behaviour. What consequences does this knowledge have for jurisdiction? How should people be treated that were identified to have a gene that makes them a potential violent criminal?

*Prof. Dr. Rainer Riemann, Faculty of Psychology and sports science, University of Bielefeld (Germany)*

**Committee 4: Personalized Medicine: increasingly diagnoses with the help of DNA analysis?**

New methods of diagnoses can ascertain people at a very early stage that they have a high risk of getting a severe disease in the future. Should this early diagnosis be obligatory for everybody? What are the threats and opportunities for the psychological health of the individual? What general regulations are necessary?

*Mara Dierssen (PhD), Faculty of Medicine, University of Cantabria (Spain)*

In each committee the students formulated resolutions which they afterwards discussed in the general assembly. After a further plenary debate, each thesis was accepted oft declined by the students. Participating in YESP students experience democratic decision-making processes, train their debating and negotiation skills and enhance their knowledge of Science.

**The 2WAYS-project – Communicating Life Science Research**

The 2WAYS project is about developing, showing and evaluating interactive and dialogical presentations of ongoing European life science research supported by the European Commission.

EUSCEA, the “European Science Events Association” ([www.euscea.org](http://www.euscea.org)) initiated the 2WAYS project.

It consists of six consortium partners located in Copenhagen-Denmark, Vantaa-Finland, Berlin-Germany, Jerusalem-Israel, Barcelona-Spain and Goteborg-Sweden, and 29 EUSCEA member organizations from 17 countries. Two member organizations form a so-called “Pair of Partners”.

Each Pair of Partners selected one recent peer-reviewed European science research project, developed a New Science Presentation together with the involved scientists and presented it in both science festivals and special science events.

# THE YOUNG EUROPEANS SCIENCE PARLIAMENT

In addition each partner carried out a scientific Impact Comparison Study to learn about the presentations' impact onto the visitors. Local Science Parliaments are organized by the partners, too. During three days 60-100 students (16-20 years old) from different local schools discussed controversial questions in the field of life science research. Each Local Science Parliament nominated two representatives who participated in the Young Europeans Science Parliament.

### **Committee 1: Use of Embryonic Stem Cells: Blessing or curse?**

What are the opportunities and threats of this technology? To what extent should Embryonic Stem Cells be used?

*We recognise:*

- A. The ethical aspects of Embryonic Stem Cell Research (ESCR) always need to be discussed in connection with the definition of a human being and cannot be divided into separate medical and ethic discourses.
- B. There are different opinions whether an embryo is the first stage of life or not, and every opinion is to be respected. This makes it hard to find a common, EU-wide consensus.
- C. The lack of co-operation and communication, together with the diverse national historic and religious backgrounds, has resulted in having no common ground. However, we strive for a united European answer in the future.
- D. The present scientific funding system promotes the research on ethically problematic fields.
- E. Embryonic Stem Cell Research has several benefits – f.e. the discovery of induced Pluripotent Stem Cells (iPS)<sup>1</sup> – but acquiring the embryonic stem cells currently implies the embryo's death.

*We demand:*

- 1. The current debate and discussion needs to be encouraged and furthered so that informed decisions may be made.
- 2. The lack of unity cannot be ignored, and therefore sensitivity and appreciation of the diversity of cultures are strongly called for. The creation of an impartial organisation with representatives from each country is strongly advisable, the ultimate resolution will attempt to be a compromise.
- 3. To inform the public about the state of ESCR and raising the general level of knowledge on the topic, a large database of information shall be created which is widely available and easily accessible. To further transparency it will also contain detailed information on companies currently researching in the field of stem cells.
- 4. Further research has to be conducted to find alternative methods of extracting stem cells without hindering the development of embryos, the current methods to obtain stem cells being:

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<sup>1</sup> *induced Pluripotent Stem Cells* are cells with the potential to differentiate into certain different cell types, but artificially derived from adult stem cells.

- i. ESCR which shall only be carried out with surplus cells of in-vitro fertilization (IVF) treatments or from aborted embryos without financial compensation,
  - ii. iPS which shall be the preferred method, as it not only doesn't harm life but also allows for better control of the therapeutic outcome.
5. More funding needs to be supplied for research that focuses on understanding the working of stem cells rather than their immediate application and use. This financial support goes hand in hand with thorough technological risk assessment.
6. Integrity, morality and good intentions have to underpin every experiment.
7. Research on induced Pluripotent Stem Cells should be encouraged and supported financially, as the creation of induced Pluripotent Stem Cells which are almost similar to Embryonic Stem Cells would render the ethical discussion obsolete.

**Committee 2: Using the results from genetic tests: What are the consequences for society?**

Genetic tests can lead to a better treatment of diseases, but who should get hold of the results? Should insurance companies or employers get access to the information? How can abuse be avoided? How can a legal environment be created that secures the privacy of the results?

*We recognise:*

- A. Genetic testing is a process during which DNA is scanned for specific traits that identify:
  - i. a certain genetic disease,
  - ii. the probability to develop certain illnesses (e.g. cancer).
- B. Usually members of families with a history of certain illnesses, such as cancer, test whether there is a genetic predisposition to these illnesses.
- C. Genetic tests are sometimes conducted by private companies that have different working standards. Thus the reliability of the results may vary in different institutes offering these examinations.
- D. Currently there are no common regulations on who can undergo genetic tests.
- E. The healthcare systems are different in every European country, especially regarding the role of private health insurance.
- F. Private insurance companies rely on a personal profile of their clients to calculate risks to offer an individual insurance policy.
- G. People with a high probability to develop a certain illness during their lifetime (e.g. cancer) might face discrimination regarding job applications or insurance policies.
- H. People who were identified as having a high probability to develop a certain disease (e.g. Cardio-vascular disease) might endanger other people's lives when carrying out a certain profession.

*We demand:*

- ~~1. Concerning professions that include carrying responsibility for other people's lives:
 
  - i. It should be optional for the employer to request job applicants undergo DNA screening for certain diseases,
  - ii. the cost of these DNA screenings has to be covered by the employer,
  - iii. applicants have to adhere to the employer's requirements if they apply for such jobs.~~
- 2. When undergoing genetic testing, the subject should be able to decide if they want to:
  - i. Make their genetic profile available to science and to be stored in international databases,

- ii. donate their DNA to scientific research and also to be stored in international databases,
  - iii. include their genetic profile in the medical record.
3. If somebody chooses to donate their DNA or genetic profile to science, their privacy still has to be ensured concerning data storage. In databases containing DNA or genetic profiles data must therefore be made anonymous by labelling data with number codes.
4. You must be at least 18 years of age to undergo genetical testing
  - i. If you are under 18 you can only be tested under the following conditions,
  - ii. if it is recommended by a doctor because of your families history concerning certain illnesses,
  - iii. if the legal guardian allows this.
5. Genetic tests should be paid for by the public, if it is recommended by a doctor due to the family's medical record.
6. Regulations concerning genetic testing have to be created to ensure a common standard and reliability of the results.
7. It also has to be ensured that clients who want to be tested get sufficient counselling and understand the benefits and drawbacks of the test prior to the examination of their DNA.
8. Regulations concerning the use of results from genetic tests for insurances should be discussed on a national level because of the differences regarding the various health care systems.

### **Committee 3: When genes trigger aggressive behaviour**

Brain research has discovered that genes control processes in our brain that might lead to aggressive behaviour. What consequences does this knowledge have for the judiciary? How should people be treated who have been identified as having a gene that makes them potential violent criminals?

*We recognise:*

- A. Research has shown that genes such as MAO-A influence aggressive behaviour when they are triggered by a negative environment.
- B. There is insufficient knowledge to fully understand the link between genes and aggressive behaviour.
- C. Certain genes may influence aggressive actions if environmental prerequisites are met, which include:
  - i. abusive or traumatic experiences during childhood,
  - ii. aggressive and negative enforcement by the environment,
  - iii. mental disorders.
- D. While the MAO-A genetic mutation is common, it is not always associated with aggressive behaviour.
- E. Genetic tests can be used to identify the gene and predict potential for violent conduct.
- F. We are concerned that people with these genes might become victims of discrimination and prejudice if the test results are made public.
- G. Our decisions are based on the information currently available, and may have to be reconsidered if research presents new results.

*We demand:*

- 1. The presence of a gene should not play a role in judicial proceedings.
- 2. We support further research to ensure sufficient understanding and reliable testing of genes by allowing voluntary genetic tests for medical and research purposes only.
- 3. All test results should remain anonymous and confidential.
- 4. Verified and reliable information about aggressive genes and potential consequences should be made available to the public by the government to prevent misinterpretation and prejudice.
- 5. The government should provide additional information about existing therapies to people tested positive for aggressive genes.

**Committee 4: Personalised medicine: Better diagnoses with the help of DNA analysis**

New methods of diagnoses can ascertain people at a very early stage that they have a high risk of getting a severe disease in the future. Should this early diagnosis be obligatory for everybody? What are the threats and opportunities for the psychological health of the individual? What general regulations are necessary?

*We recognise:*

- A. Scientific knowledge in the field is rapidly evolving and constantly changing.
- B. Results of genetic tests can be misinterpreted and invalidated by new discoveries.
- C. The general public lacks information on the issue of genetic testing.
- D. Currently, companies offering genetic testing are not legally regulated leading to possible adverse effects for their clients.
- E. Prices for personalized genetic testing are still relatively high.
- F. The results of genetic testing can have devastating psychological or psychosomatic effects.
- G. There are conflicts surrounding an age of consent in respect to genetic testing.
- H. An ethical dilemma concerning prenatal testing exists.
- I. Information provided by genetic testing is highly sensitive and its publication could be harmful to the person affected.

*We demand:*

1. An EU body of scientists must re-evaluate the scientific knowledge in the field on a regular basis.
2. A central EU institution should regulate and provide licenses to official institutions and private companies offering genetic testing.
3. Genetic testing should only take place after a consultation with a specialized doctor and has to be followed up by another consultation - once results are available - in order to minimize possible misinterpretation.
4. Given a medical indication, genetic testing should be paid for by the public/health insurance.

5. Follow-up counseling by a psychologist should be compulsory, free of charge in case of a test done after a doctor's recommendation and highly recommended in case of voluntary testing but at the person's own expense.
6. Genetic testing of minors should be limited to tests for treatable diseases and only happen on the parents' initiative and a medical doctor's recommendation.
7. Prenatal testing should be limited to monogenetic diseases and severe chromosomal aberrations.
8. Information from genetic tests belongs to the patient (respectively their guardian) and is protected under the doctor-patient confidentiality.