

***Starting a Debate  
with Women Scientists from Post-Communist  
Countries on Ethical Issues***

CONTRACT NO. 503316

**Periodic and Final Activity Report**  
(for the period of June 1 2003 – May 31 2004)

LU ET APPROUVE

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~~Alfon~~  
12/20/04

### **Objectives of the project**

The main objective of the project was to identify together with women researchers from the post-communist countries, namely in the Central Eastern European countries and in the Baltic States, if there is a gender dimension concerning science-related ethical issues, like for example sensitive questions brought into the forefront of interest by the advance of biotechnological methods. It was also the intention of the project to assess whether there exists a specific sensibility related to the above issues in the post-communist countries, with special regard to the fact that the political system restricted the approach to sensitive information and that the general atmosphere during the communist regime did not allow to publicly discuss ethical problems in any areas of life (e.g. religious matters, euthanasia, genetics, etc.).

The project was developed under Action 27 of the "Science and Society Action Plan" of the European Commission: a STRATA ETAN Expert Group „Promoting women scientists from the Central and Eastern European countries and the Baltic States to produce gender equality in science in the wider Europe (Enwise)". It addressed one of the specific activities planned under section 3 of the Terms of Reference of the Enwise Expert Group: "a workshop with women scientists involved in ethical issues to express their views on a few selected topical issues such as, for instance, stem cells embryo, etc."

The workshop was also connected to three other aims of the Science and Society Action Plan. First of all to section 3.1, "The ethical dimension in science and the new technologies", and especially to Action 30 within it. According to this initiative "an open dialogue will be established between NGOs, industry, the scientific community, religions, cultural groups, philosophical schools and other interested groups, stimulating an exchange of views and ideas on a range of critical issues, such as the ethical impact of new technologies on future generations...." The target of the event was also closely related to "Public awareness (1.1)" and to "Involving the civil society (2.1)".

The specific objectives were to bring the ethical aspects of biomedical research into the forefront of interest in Hungary, but also in the other countries, with the aim to show both to women and decision makers what is at stake and call the attention of the women scientists in the postcommunist countries to become more active and express their opinion.

## **Overview of activities and progress during the project period**

### Preparatory activities

#### *1st meeting of the Steering Group (SG)*

The first meeting of the Steering Group was held in Budapest, on June 24 2004. The SG consisted of 4 Enwise group members (Bulgaria, Hungary, Romania and the Italian rapporteur of the Enwise group), the Hungarian Helsinki Group delegate, 2 representatives from EC Research DG (Women and Science Unit, Ethics and Science Unit), and several Hungarian experts involved in Women and Science issues.

The SG discussed the suggested topics sent by e-mail previously, decided on the key topics of the workshop (Ethical and gender issues in stem cell research and tissue transplantation and Ethical and gender aspects of genetic testing, storage and use of genetic information), the four main aspects (scientific, philosophical, legal/political and societal/social) along which the debate will proceed, the possible keynote speakers and the method how the participants will be selected (see the minutes of the meeting as Attachment 1).

#### *Invitation of speakers and participants*

In the next phase the program of the workshop was compiled and discussed by e-mail between SG members, then the final program was prepared. The keynote speakers were identified and invited by the end of July 2003. The speakers came from the following countries: Austria, Bulgaria, Estonia, Germany, Hungary, Italy, Latvia, UK and the EC. The speakers were asked to send the abstract of their presentations as well as their CV by September 15.

The interested/concerned women scientists in each Enwise country (Bulgaria, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Romania, Slovakia, Slovenia, the German Eastern Länder and the Balkan countries) were selected by using the help of the local Enwise representatives and the national Helsinki group members.

After finding the women willing to participate in the workshop (2 participants/country), they were invited to Budapest. Before the event the airplane tickets were ordered by the coordinator for those who asked for it. Other participants bought their own tickets and were reimbursed after the workshop.

#### *Other preparatory activities*

The venue of the workshop was selected after asking offer from different hotels. Hotel Budapest (member of the Danubius chain) gave the best bid for both the rooms and the conference facility. The rooms were reserved well in advance to receive the lowest rate possible.

The technical preparations (hotel reservation, ordering workshop supply, catering etc.) were started in September.

A folder was prepared for each participant, containing the program of the workshop, the list of participants, the short CV of keynote speakers, a list of the Enwise experts and some information material.

## The workshop

The workshop took place on October 2-3, in Budapest, Hungary. It was a restricted working event organised only on invitations. A total of 48 participants were present, including also the speakers. The audience came from the Enwise countries (Bulgaria, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Romania, Slovakia, Slovenia, the German Eastern Länder and the Balkan countries), representing different scientific fields. From Hungary 20 participants were present at the workshop, including women (and some men) scientists working in relevant fields of research, lawyers, journalists and invitees from local women's organisations. The participants were carefully selected in order to ensure balanced representation of the scientific, philosophical, legal/political and societal/social aspects of the bioethical issues debated during the workshop.

The workshop started with introductory remarks given by Dr. Andras Siegler, Deputy State Secretary of the Hungarian Ministry of Education, heading the Division of Research and Development (this institution was at the time of the event the governmental responsible body for the implementation of FP6 in Hungary). The general presentation given by the representative of the Women and Science Unit of the European Commission's Research DG (Brigitte Degen) provided information on the Women and Science activities - in particular on the Enwise activities - of the Commission. The next presentation was given by the Head of the Science and Ethics Unit, EC DG RTD (Barbara Rhode) on the significance and management of ethical issues in the 6th Framework Programme. The first keynote speaker (Elisabeth Hildt) gave an overview on ethics in science from a gender perspective, with special emphasis on reproductive medicine, women and autonomy. Then a well-known science journalist (Sylvie Coyaud) spoke about bioethical issues in the media, raising the question whether women can make a difference in the life sciences.

In the afternoon the workshop continued with two parallel sessions, dealing with *Ethical and gender issues in stem cell research and tissue transplantation* and *Ethical and gender aspects of genetic testing, storage and use of genetic information*. The keynote presentations of the sessions were given by experts, who elucidated different aspects (scientific, philosophical, legal/political and societal/social ) of the scientific question offered for debate. First a scientist with high-level expertise in the given topic gave an explanatory presentation on his/her research field using terms,

which can also be understood by those participants who are not familiar with the topic. Then philosophers analysed the possible directions of research and the potential use and dangers of research results. The legal aspects of gender issues in biomedical research were raised by a chief university legal advisor and a lawyer working in research. Finally speakers representing the public (a journalist and an NGO leader) added their remarks. The developing debates were led and moderated by the Enwise-member chairpersons of the sessions (Mioara Tripsa and Nikolina Sretenova), and their work was helped by rapporteurs.

In the evening a 90-minute film titled "Our Cells" by Tamás Almási was shown to the participants. This international award winning film on in vitro fertilization was received with great interest. The broadcasting was followed by informal discussion with one of the main characters in the film, Katalin Kanyo.

On the second day a high-level representative of the Hungarian state body responsible for gender mainstreaming (Borbála Juhász, Governmental Office of Equal Opportunities) gave information to the audience about the state policy on gender equality in the postcommunist countries, and specifically in Hungary. Then József Mandl, the Secretary of the Hungarian Ethics Committee (Medical Research Council) spoke about the role, tasks and responsibility of the ethics committees in general.

In the plenary meeting the chairpersons of the parallel sessions summarized the results of the previous day' debate (see the reports on the parallel sessions in Attachment 2) and draw some conclusions on the session's respective topics.

The workshop was concluded with a general debate and by formulating the recommendations which became included in the Enwise report.

### Workshop follow-up

The presentations were collected after the workshop.

Using the workshop material a publication was compiled consisting of Introduction, Program, List of participants, Short CV of keynote speakers, Presentations, Report on the debates and Recommendations.

## Results and conclusions

Presentations and consecutive discussions indicated that women scientists of the Enwise countries are highly interested in present ethical/bioethical debates, on the background of both the heritage of the past and the new challenges connected to the EU enlargement and the ongoing processes of globalisation. Women in post-communist countries have strong and often controversial opinions regarding the recent development of biotechnologies, the role of the scientist and the meaning of human life. Yet a broader public debate is still lacking and awareness campaigns about these crucial questions have not yet really started.

During the workshop, participants stressed that science seems to have developed at a much faster rate than domestic legislations and regulations could follow, especially in Enwise countries where the transitional shift from communist regimes to the perspective of EU enlargement induced a radical transformation of previous political, cultural, socio-economic and legal environments. Therefore, a stronger process of democratisation is required also in the bio-ethical field, where civil society, science and politics are interconnected. A bottom-up approach and the consideration of public opinion are the best means for the correct handling of (bio)ethical issues. A grave concern related to the lacking or insufficient regulatory, as well as public, control of outsourcing ethically sensitive biomedical research to the Enwise countries was formed. Scientists need to contribute to the education of the general public. Yet in the area of exchange of genetic information, the responsibility of scientists/ doctors and the position of women in related decision making should also be considered. Concerns about the potential abuse of genetic data for national interests or for stigmatisation of minorities were also stressed during the workshop's debate. In addition, the role of the media in providing correct information and promoting adequate public campaigns was indicated as one of the priorities: science journalists should provide an accurate information in the dissemination of scientific research and results. Transparency in bioethical issues should be also increased by a better representation of different stakeholders (women, social scientists, etc.) in ethics committees and by introducing these committees' tasks and role to the public.

## Recommendations

- \_ Responsible state bodies (ministries, etc.) and/or public organisations should initiate public debates on (bio)ethical issues, with special emphasis on questions and topics concerning women. Awareness campaigns should also be launched.
- \_ Ethics Committees should be made better known among the general public and their decisions should be more *transparent*.
- \_ When selecting the members of Ethics Committee, a gender balanced composition (i.e., at least 40% female members) and the representation of different viewpoints (social science, philosophy, etc.) should be looked for to ensure a greater diversity in their composition.
- \_ Womens' scientific communities should initiate cooperation among colleagues from different disciplines and promote public initiatives about gender and ethical issues in science. These should in particular focus on informing women on gender aspects of new scientific developments.
- \_ Scientists should play their role in disseminating information on new scientific developments to the general public and in explaining the possible gender aspects of those results, so that the purpose of research and the systems that regulate it can be better understood.
- \_ Science journalists are urgently needed to participate in the dissemination of accurate information on medical and biotechnological developments and in the *objective* explanation of possible risks. In this context, DG Research should strengthen its network of science journalists and feed it with more information.
- \_ The Budapest workshop was intended as a starting point in a series of open debates related to science and society in different societal settings and countries. Further initiatives and follow-up are thus necessary in order to increase public and scientific awareness on ethical/bioethical issues, and it is of course essential to include a gender perspective in all further debates.

### **Plan for using and disseminating knowledge**

The brochure containing the edited material of the workshop will be published by the European Commission. The publication will be disseminated at the occasion of the valorisation conference of the Enwise report: „Enlarging Europe with/for Women Scientists” (Tallin, September 9-10, 2004) and by the Enwise group experts in their respective countries.

## Attachment 1:

### Minutes of the meeting of the Enwise Ethics Workshop Steering Group

(Budapest, June 27 2003)

#### Present:

Dora Groo, Brigitte Degen, David Coles, Marina Calloni, Nikolina Sretenova, Mioara Tripsa, Ildiko Hrubos, Attila Zsigmond, Zsuzsa Herczeg, Judit Thorma Asboth, Maria Palasik, Eva Salamon, Gabor Porzse, Gergely Csonkareti, and Maram Anbar.

1. Welcoming address by **Dora Groo** defining the aims of the meeting and the expected results for the preparation for the October workshop. Agreement on the proposed agenda, no amendments.

2. Introduction to the Enwise initiative by **Brigitte Degen**. Enwise Ethics project is the first successful project through the Science and Society open call in this area. Women and Science activities started in 1999, when an EU expert group wrote a study on the topic (ETAN Report). It was followed by setting up the Helsinki Group on Women and Science and two reports have been prepared by its members (the Helsinki Group Report and the WIR Report).

The gender issue in post-communist countries encounter new challenges and rapid changes. Therefore, before the enlargement process actually takes place, an expert group was set up by the European Commission to promote women scientists from the Central and Eastern European countries and the Baltic States to produce gender equality in science in the wider Europe (Enlarge Women and Science to the East - Enwise).

3. Introduction to the Ethics and Science Unit by **David Coles**. The fact that all proposals submitted in FP6 are subject to ethical review helps people writing proposals to think more thoroughly about the ethical issues in general, and more specifically to evaluate their proposal on whether or not it addresses ethical issues. The attention has been directed to ethical issues in general; a development in the quality of addressing these issues can already be seen.

The unit is gathering data on ethical regulation in the Candidate Countries, and a report will presumably be published at the end of 2003, to serve as a reference document.

4. Introduction of the Steering Committee members and the attendees of the meeting.

5. The Steering Committee agreed that the timing and format of the programme of the October workshop is appropriate as proposed by **Dora Groo (see Annex 1)**.

The committee decided to **rephrase the title** of the workshop to reflect its content and the new title is: "**Debating bioethical issues with women scientists from the Enwise countries**".

The aim of the workshop is **not** to find out the difference in the way of thinking between EU member states and Candidate Countries but rather to give the possibility for CCs to express their opinion, in particular to women scientists and women from the civil society.

## 6. The selection of topics

The selected topics have a lot of potential and reflect a number of issues. Some of the areas mentioned are banned for the moment such as human cloning.

There are **two** areas that were not mentioned in the document of suggested topics: one is **DNA Banking/storing** and linking it to medical records (a topic which presumably attracts interest from commercial companies, as well). The other direction is linked to **setting standards**, guidelines, and legislations for ethical issues. Especially after the development of functional food, and clinical trials for children's food.

The Steering Group agreed to select the following **two topics for the parallel sessions**:

Suggested topic 5. Ethics, Stem Cell Research and Tissue Transplantation

**New title:** Ethics and gender issues in stem cell and tissue transplantation

Suggested topic 4. Ethics, Diagnosis and Prevention of Human Genetic Disease, and Classification and Conservation of Genetic Information

**New Title:** Ethical and gender aspects in genetic testing, storage and use of genetic information.

## 7. Identification and selection of keynote speakers

The speakers in each topic should come from different backgrounds and will cover **4 main areas/disciplines**:

- Science
- Philosophy
- Legal/regulatory aspects
- Social/societal issues

A number of speakers were suggested by the members of the steering group for the two selected topics and the plenary sessions (**see Annex 2**). It was agreed upon that **July 4<sup>th</sup>** will be the **deadline** for further contribution and updates to the suggested list.

## 8. Identification of participants

Participation in the workshop will be restricted due to the limited number of places therefore attendance will be by invitation. A list of possible candidates from Hungary was presented (**see Annex 3**). The agreement was that participants should come from different backgrounds and disciplines including NGOs. A special attention will be given to young scientists.

Gender equality: to this workshop, mainly female participants will be invited.

## 9 Discussion and pending issues

The need for a mailing list of the people present at the meeting (**see Table 1**).

### Deadlines:

July 4	Presenting a list of possible/tentative keynote speakers
July 31	Deadline for the Enwise group to delegate or suggest delegates
	from their countries
September 15	Providing/suggesting background material to be used for the workshop

## Attachment 2:

### Report on the two parallel sessions' debates

Session I:

#### Ethical and gender issues in stem cell research and tissue transplantation

Chairperson: Mioara Tripsa, RO

Rapporteur: Gábor Pörzse, HU

Speakers: András Dinnyés, HU

Herlinde Pauer-Studer, A

Sylvia Tomova, BG

Anna Mátay, HU

#### Scientific highlights:

- Latest development of the field resulted in generation of germ cells (both oocytes and sperm) via cloning technology and embryonic stem cell isolation in animal models. This method would allow males to generate oocytes and sperm, but only oocytes for females.
- Creation of parthenogenetic embryos for stem cell isolation would allow only woman to have own cell therapy cells from embryos, which would not be able to develop into babies.
- Mixed animal oocyte and human somatic cell embryos might generate embryonic stem cells, therefore it might become possible to generate the cells without sacrificing human oocytes in the process.
- Philosophical approach highlighted the need for “freestanding arguments” independent from personal views.
- Media case study of a recent controversial debate on umbilical cord blood collection in Hungary highlighted the lack of correct information and follow up in media, despite high frequency of reports on the case.

#### Conclusion:

No regulations have been formulated for the very recent scientific developments. A designated scientific correspondent searching for relevant news would allow the EC to shorten reaction time on relevant scientific developments.

Furthermore, such developments highlights the fact, that science develops at a much faster rate, than ethical and legal discussion and legislation would be able to follow. Also, the diversity of the Enwise countries on regulations and public opinion makes such a task extremely difficult. Therefore, a bottom up approach might be more efficient for the future of stem cell research and applications. It would be based on the fundamental rights of freedom to reproduce, allowing individuals to seek ways to achieve that via newly developed techniques, instead of the presently applied, strictly regulatory approach. Risk assessments and quality control could replace the regulations based on the common ground of a very diverse society.

Strict regulations are driving leading research abroad and underground, as medical needs creates a market for “offshore” high tech medical services, in that case without any control of the society and scientific community, and restricted only for the richest segment of the society. This situation must be avoided to happen in Europe.

Session II:

**Ethical and gender aspects of genetic testing, storage and use of genetic information**

Chairperson: Nikolina Sretenova, BG

Rapporteur: Beáta Scholtz, HU

Speakers: Mara Marga, LV

Margit Sutrop, EE

Judit Sándor, HU

Alastair Kent, UK

The presentations and debate emphasized three key issues:

**1. Exchange of information: patients and scientists-doctors**

There is a big responsibility when disclosing info either from genetic testing, or from results of research from genetic databases - the system has to be flexible, and take into account the following. a) Need for disclosure varies – not everyone requires it, and people can change their minds over time. b) Not all genetic info is equal – sometimes it is only information, and no decisions can be made, no actions can be taken. c) If required by the patient, though, as complete info as possible has to be provided, making sure that the individuals understand: what the results mean, risks involved, possible therapies, and what it is to live with that disease. People can be trusted to make sensible decision if provided with info and opportunity to decide. d) The question can be raised, whom should the results-info be shared with, disclosed to – transgenerational issues, results affect not only the individual, but also the family. Special conditions for Poland: abortion is not legal. There is increased pressure about stopping prenatal genetic testing.

Society is expected to provide the framework for good genetic counseling, and to encourage the formation of patient support groups, to educate the general public to increase acceptance – this needs financial resources. If this infrastructure is not provided, the danger of coercive decisions increases, i.e. through pressure from family, community, society.

It was recognized that knowing the results of genetic tests/research put an enormous burden on women – decisionmaking is expected from them. Often it is assumed that women have a duty to know results, for the good of the family. Genetic counseling can follow different strategies by male or female doctors.

**2. Exchange of information: between patients and society**

In terms of biobanking-genetic banks, sharing of one's genetic information (through providing a sample) can be expected, and usually accepted by the individuals, for the benefit of the society (curing, preventing disease, helping with crime) and for the benefit of a particular patient group.

Society, on the other hand, needs feedback about the quality of life with a disability, and patient advocacy or support groups have an enormous role in this – make yourself visible!

**3. Exchange of information between scientists/doctors and a third party**

This requires strict regulation, especially because anonymization is not always possible, and not always sought. Society is expected to recognize the need for data security and privacy, to provide the criteria and means for secure data storage, as well as to educate the public about possible interpretation of data from genetic programs. Education is especially necessary since the results can be abused e.g. for nationalistic interests, but also for stigmatization of minorities.

#### 4. Scientists and society

Continuing communication is needed to make the public opinion and scientific opinion known to each other. Informed consent should be given at two levels: from the community, and from the individual. Scientists need to contribute continuously to the education of the general public – responsible leadership of the society needs to prompt this contribution, and provide the framework for it. This again needs funding. Also, science journalists are urgently needed to participate in dissemination of accurate information.

How transparency/regulation can be achieved?

- Providing accurate information to general public is critical, so that people can understand the purpose of proposed studies / biobanks and the system that regulates them
- Ethics Committees should be made known, as well as selection criteria for Committee members
- Gender balanced Ethics Committees are needed
- Representatives of social scientists, philosophers are needed to sit on Ethics Committees
- International oversight of Ethics committees can be beneficial-
- Ensure objectivity and independence of Ethics Committees

#### **Concluding remarks:**

- During the workshop, participants stressed that science is developing at a much faster rate than domestic legislation and regulations can keep up with, especially in the Enwise countries, where the transitional shift from communist regimes to market economies resulted in a radical transformation of previous political, cultural, socio-economic and legal environments. Therefore, a stronger process of democratisation is required, in particular in the bio-ethical field, where civil society, science and politics are interconnected, where women -and in particular women scientists- could play an important role. A bottom-up approach and the consideration of public opinion were seen as the best means for the correct handling of (bio) ethical issues.
- Transparency in bioethical issues should also be ensured by a better representation of different stakeholders (women, social scientists, etc.) in ethics committees and by introducing the role and tasks of these committees to the general public.
- Participants underlined, with concern, the lack or the insufficiency of regulation, and of public control, on the out-sourcing of ethically sensitive biomedical research in the Enwise countries. Yet in the area of the exchange of genetic information, the responsibility of scientists/medical doctors and the position of women in related decision-making should also be considered. Concerns about the potential abuse of genetic data for national interests, or for the stigmatisation of minorities, were also expressed during the debates.
- Scientists, and in particular women scientists, should pay more attention to the inter-relation and inter-action of gender and ethics in new scientific developments.
- Scientists should not exclude themselves from the education of the general public, nor the media, the role of which was indicated as a priority. Science journalists should provide accurate information in the dissemination of scientific research and should participate in promoting adequate public information campaigns.

### **Recommendations for the Enwise final report**

- Responsible state bodies (ministries, etc.) and/or public organisations should initiate public debates on (bio)ethical issues, with special emphasis on questions and topics concerning women. Awareness campaigns should also be launched.
- Ethics Committees should be made better known among the general public and their decisions should be more *transparent*.
- When selecting the members of Ethics Committee, a gender balanced composition (i.e., at least 40% female members) and the representation of different viewpoints (social science, philosophy, etc.) should be looked for to ensure a greater diversity in their composition.
- Womens' scientific communities should initiate cooperation among colleagues from different disciplines and promote public initiatives about gender and ethical issues in science. These should in particular focus on informing women on gender aspects of new scientific developments.
- Scientists should play their role in disseminating information on new scientific developments to the general public and in explaining the possible gender aspects of those results, so that the purpose of research and the systems that regulate it can be better understood.
- Science journalists are urgently needed to participate in the dissemination of accurate information on medical and biotechnological developments and in the *objective* explanation of possible risks. In this context, DG Research should strengthen its network of science journalists and feed it with more information.
- The Budapest workshop was intended as a starting point in a series of open debates related to science and society in different societal settings and countries. Further initiatives and follow-up are thus necessary in order to increase public and scientific awareness on ethical/bioethical issues, and it is of course essential to include a gender perspective in all further debates.