

**MEDICAL UNIVERSITY OF PLEVEN
FACULTY OF PUBLIC HEALTH**



DAY OF BIOETHICS

06.04.2017

BOOK OF ABSTRACTS

Pleven, 2017

The Day of bioethics is an initiative originated by Prof. Dr Silviya Aleksandrova-Yankulovska. The first Day of bioethics was held on 8.04.2014 and was dedicated to research ethics. Invited speaker was the distinguished bioethicists *Prof. Henk ten Have*, Doctor Honoris Causa of Medical University of Pleven. Prof. ten Have also moderated the ethical case analysis poster session with the participation of 13 medical students English division of Medical University of Pleven. All full texts of the materials were independently reviewed by Prof. ten Have and Prof. Silviya Aleksandrova-Yankulovska and were published in the book “Ethical decision-making in health care”. The book also serves as a valuable study material in the course of bioethics for medical students.

The Day of bioethics 2015 was dedicated to human rights in health care. Invited speakers were *Prof. Luciana Caenazzo* - Professor in legal medicine and bioethics, Department of Molecular medicine, University of Padua and *Prof. Renzo Pegoraro* - Professor of Bioethics at Faculty of Theology, University of Padua, Past-President of the European Association of Centers of Medical Ethics, and Chancellor of Pontifical Academy for Life.

The Day of bioethics 2016 was focused on Aging Ethics. Invited speaker for second time was *Prof. Renzo Pegoraro*. Plenary lectures also delivered *Prof. Dr Silviya Aleksandrova-Yankulovska* and *Assoc. Prof. Valentina Kaneva* from Sofia University “St. Kliment Ohridski”.

The Day of bioethics 2017 is organized under the moto “Ethics in practice” creating wide platform for discussions about the practical application of ethics in medicine. Invited speaker is *Dr. Els Maeckelberghe*, senior university lecturer in ethics at the University Medical Center Groningen.

All presenting authors are encouraged to publish full text of their reports and posters in the Medical University of Pleven Journal of Biomedical and Clinical Research: <http://jbcr.mu-pleven.bg/>

Invited speaker



Dr. E.L.M. (Els) Maeckelberge was born in Oostende, Belgium, October 12 1961.

She studied at the Catholic University of Louvain, Belgium where she received an MA in Religious Studies (Magna cum laude) in 1984 and an MA in Theology (Magna cum laude) in 1985.

She worked as a researcher at the University of Groningen, the Netherlands where she defended her PhD dissertation in 1991. Title Thesis: *Desperately Seeking Mary. A Feminist Appropriation of a Traditional Religious Symbol.*

Kampen: Kok Pharos, 1991. Promotores: Prof. LA Hoedemaker, Prof. P Vandermeersch, Prof. M. Grey

She worked as a university lecturer at the Faculty of Theology and Religious Studies of the University of Groningen (The Netherlands) where she also was the co-ordinator of the Master Programme Spiritual Care Studies.

Since 1999 she is a senior university lecturer in ethics at the University Medical Center Groningen, University of Groningen, The Netherlands, with a focus on research ethics, scientific integrity, and health care ethics. She has extensive teaching experience.

Her research projects are about implementing moral knowledge in health care practices and guidelines (pediatric euthanasia, pediatric medical research, big data, technological innovations).

Current projects:

- Uptake and effectiveness of a Dementia Risk Reduction Program in middle-aged descendants of demented people due to Alzheimer Disease or Vascular Dementia: a road map to healthy ageing.
- Physicians as change agents: Transformational learning in Learning Communities: Medical Curriculum G2020 Groningen.
- Big data and the dilemma of innovative knowledge versus threats to personal integrity.

- Children's participation in clinical trials: experiences of and with children.
- End-of-life decisions and palliative care for children.
- The development of a preventive telecare solution in a societal responsible way.

She was initiator of the Section Ethics in Public Health of EUPHA (European Public Health Association) where she served as president from 2008-2014. She currently is vice-president of this Section.

She was Co-chair of the ASPHER-EUPHA Working Group on Ethics and Values in Schools of Public Health (ASPHER: *Association of Schools of Public Health in the European Region*) (2010-2015).

Since 2010 she is Chair EUPHA (European Public Health Association) working group on private sector collaboration.

She is active as member of several boards and committees:

2017-curr	Ethics consultant 'Working group on complex care' "Alliade" (health care organization for people with disabilities)
2011- curr	Member Medical Ethics Review Board University Medical Center Groningen
2010- curr	Ethics member Regional Euthanasia Review Committee
2009-2017	Member Board of Trustees "De Zijlen" (health care organization for people with disabilities)
2003-2010	Member Board of Trustees Tjongerschans Hospital, Heerenveen
2003-2011	Chair Consultancy Board 'Ethics in Health Care' (postdoctoral professional training Nijmegen)
2001-2007	Chair Moral Deliberation Working Group Dutch Council of Churches
2000-2004	Board member 'Catherine Halkes' Foundation
1994-2015	Member Medical Ethics Review Board 'Beoordeling Ethiek Bio-Medisch Onderzoek' Foundation
1996-2008	Chair Ethics Committee ('t HeechhoutKaai) Talant (health care organization for people with disabilities)

PROGRAMME

Hall “Ambroise Pare”, Telecommunication Centre, MU-Pleven

9:00 – 9:15	Opening and welcome address by the Rector of Medical University - Pleven, Prof. Dr Slavcho Tomov, MD, PhD, DSc
9:15 – 10:45	Skills building workshop: Scientific integrity – part 1 <i>Speaker: Dr Els Maeckelberghe</i> , Senior lecturer ethics in medicine, University medical center Groningen, The Netherlands; Vice-president of Section of Ethics in public health of European Public Health Association; Regional Euthanasia Review Committee. <i>Moderator: Prof. Dr Silviya Aleksandrova-Yankulovska</i>
10:45 – 11:00	Coffee break
11:00 – 12:30	Skills building workshop: Scientific integrity – part 2 <i>Speaker: Dr Els Maeckelberghe</i> , Senior lecturer ethics in medicine, University medical center Groningen, The Netherlands; Vice-president of Section of Ethics in public health of European Public Health Association; Regional Euthanasia Review Committee. <i>Moderator: Prof. Dr Silviya Aleksandrova-Yankulovska</i>
12:30 – 13:30	Lunch break
13:30 – 15:30	Round table - Euthanasia <i>Moderators: Dr Els Maeckelberghe</i> <i>Prof. Dr Silviya Aleksandrova-Yankulovska</i> 1. Introductory presentation <i>Dr Els Maeckelberge, UMC Groningen</i> 2. Child Euthanasia – appeal for ethical understanding <i>Ass. Prof. Atanas Anov, MU-Pleven</i> 3. Palliative sedation for terminally ill patients <i>Assoc. Prof. Dr. Nikolai Yordanov, MD, PhD, COC-Vratsa</i>
15:30 – 15:45	Coffee break

15:45 – 17:30	Oral presentations <i>Moderators: Dr Els Maeckelberghe</i> <i>Prof. Dr Silviya Aleksandrova-Yankulovska</i> 1. Respect for Autonomy against Hospitals Guidelines <i>Prabesh Angbuhang, medical student 5th year, MU-Pleven</i> 2. Managing Ethically Related Issues in Everyday General Practice <i>Hania Abbasi, medical student 6th year, MU-Pleven</i> 3. Distinct Ethical Challenges Surrounding Surgery: Surgical Innovation, Surgical Teaching and the role of a Surgeon in the Balance of Patient Care <i>Syed Mohsin Hussain, medical student 6th year, MU-Pleven</i> 4. Ethical Issues in Genome Editing using CRISPR/Cas9 System <i>Ammad Fouzi, medical student 3^d year and Azka Fouzi, medical student 4th year, MU-Pleven</i> 5. The influence of pharmaceutical companies on healthcare <i>Gurpreet Kaur and Jency Mathew, medical students 5th year, MU-Pleven</i>
17:30	Closing

Organizer of the Day of Bioethics

Prof. Dr. Silviya Aleksandrova-Yankulovska, MD, PhD, DSc, MAS

Dean of Faculty of Public Health, Head of Department of Public Health,
Medical University - Pleven

Phone: 0035964884196

e-mail: dean-ph@mu-pleven.bg

9:00 – 9:15

Opening and welcome address by the Rector of Medical University of Pleven, Prof. Dr Slavcho Tomov

Plenary sessions

9:15 – 10:45

Skills building workshop: Scientific integrity – part 1

Dr. Els Maeckelberghe

University Medical Center Groningen, The Netherlands

Background:

Researchers are passionate about science, and doing it right. Science is what keeps us going – the curiosity for how the world is built and how things come to exist – and if we want to explore that, we have to do it in a good way. That means methodologically and ethically good. Fraudulent behaviour in science is unacceptable and most researchers would never dream of straying from the methodological and moral norms of science. Researchers, however, are just like ordinary people: they are honest, but every now and then, there are small choices they need to make that could endanger their honesty. There are many temptations to deviate from the norms of good science. These digressions undermine the trustworthiness of science.

Objectives:

- Recognise ethical issues in daily research practice
- Discussing opportunities to deal with ethical issues in research
- Understanding and applying the principles of good research

Format:

There will be a short introduction to the workshop (15 minutes) setting the stage for the average day decisions that make each and every researchers work morally challenging.

During the workshop we will watch/play *Integrity Factor*. This is a film focusing on a PhD student at the beginning of her doctoral research and using a choose-your-own-adventure structure. The audience decides how to respond to realistic scenarios where there is potential for misconduct.

In this workshop, after each scene, the participants will discuss the options and decide together what to do in these specific cases. They will learn a lot about the decisions they make, in what context they are set and why small deviations are often harder to deal with than blatant misconduct.

It promises to be a Very Interactive Workshop (VIW) where participants decide on the outcomes.

See: www.integrityfactor.nl

Main messages:

- Small temptations to deviate from the norms of good science can undermine the trustworthiness of science.
- Scientific integrity is about the courage to openly discuss what ‘good’ research is about.

10:45 – 11:00 Coffee break

11:00 – 12:30

Skills building workshop: Scientific integrity – part 2

Dr. Els Maeckelberghe

University Medical Center Groningen, The Netherlands



12:30 – 13:30 Lunch break

13:30 – 15:30

Round table - Euthanasia

Moderators: Dr Els Maeckelberghe and Prof. Dr Silviya Yankulovska

Introductory presentation

Dr. Els Maeckelberghe

University Medical Center Groningen, The Netherlands

The Netherlands: Criminal code

- The inclusion in the Criminal Code of a special ground for exemption from criminal liability means that physicians who terminate life on request or assist in a patient's suicide will not be prosecuted, provided they satisfy the statutory due care criteria and notify death by non-natural causes to the appropriate regional euthanasia review committee.



ELMM



Main aims policy in the Netherlands

1. create legal certainty for doctors caught in conflicting obligations,
2. provide transparency in the practice of euthanasia and public scrutiny,
3. to safeguard, monitor and promote the care with which medical decisions about termination of life on request are taken and the quality of such decisions by bringing matters into the open and applying uniform criteria in assessing every case in which a doctor terminates life.



ELMM



Criteria due care

- a. be satisfied that the patient's request is voluntary and well-considered;
- b. be satisfied that the patient's suffering is unbearable, with no prospect of improvement;
- c. inform the patient of his or her situation and further prognosis;
- d. discuss the situation with the patient and come to the joint conclusion that there is no other reasonable solution;
- e. consult at least one other physician with no connection to the case, who must then see the patient and state in writing that the attending physician has satisfied the due care criteria listed above;
- f. exercise due medical care and attention in terminating the patient's life or assisting in his/her suicide.



ELMM

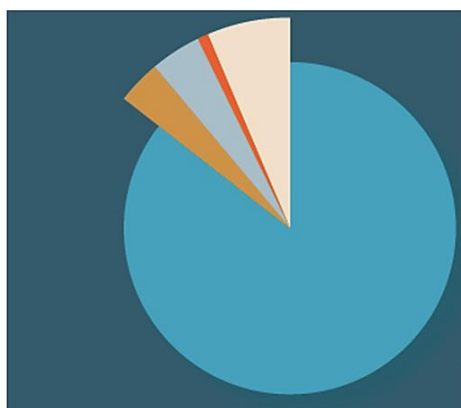
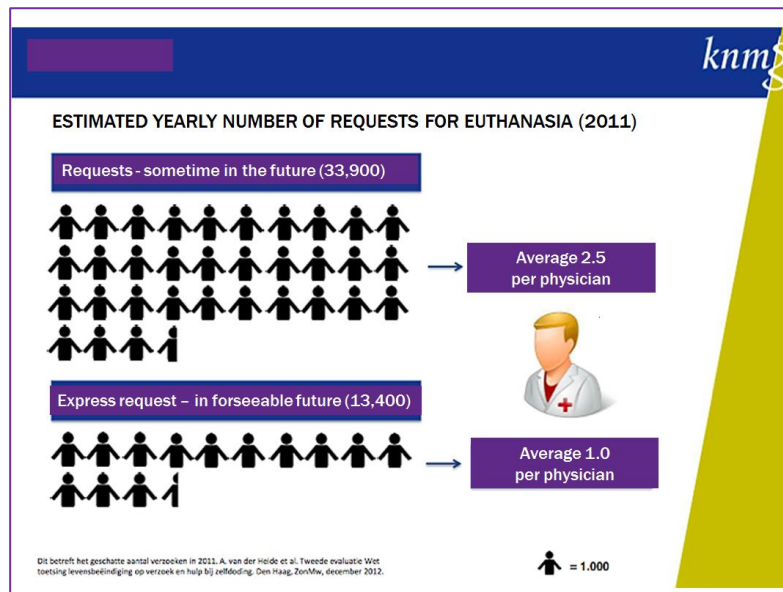


Independent Physician

- In the Netherlands a network has been set up of general practitioners and other physicians trained to provide expert assessments. This network is known as the “Euthanasia in the Netherlands Support and Assessment Programme” (Steun en Consultatie bij Euthanasie in Nederland, SCEN) and is attached to the Royal Dutch Medical Association (Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst, KNMG).



ELMM



Reporting physicians in 2015

general practitioner	4730
specialist (in hospital)	180
geriatrician/nursing home specialist	216
resident	45
physician, other (f.i. doctor in medicine, not practicing physician, etc.)	345
<i>of which associated with 'Levensindicliniek'</i>	366



ELMM



Discussion case 1

I can't breathe

- A patient in her seventies
- Since 9 years: pericardial and pleural effusion
- One year before she died: pulmonary hypertension
- Daily life activities: impossible because of her condition
- Bedridden, completely dependent on others
- Feels powerless/impotent. No quality of life. Fear of choking.



ELMM



Discussion case 2

Too much pain

- A woman, in her sixties, 6 months before she died: relapse of renal cancer with metastases in small intestine, major blood vessels and the major (spinal) nerves
- Two weeks before time of death: unbearable pain. Own GP is on holiday. Acting GP thinks there is not sufficient time for a euthanasia procedure (explicitly requested by the patient) and suggests palliative sedation



ELMM



Child Euthanasia – appeal for ethical understanding

Atanas Anov, Department of Public Health Sciences, MU-Pleven

For the last three years Belgium has become famous for “keeping the fire going” in euthanasia debate. In 2014 Belgium’s Parliament lifted all age restrictions on euthanasia and in the middle of September 2016 the first child euthanasia was performed.

This report aims at presenting child euthanasia case and would try to create ethical understanding about it. The method used for presenting and analyzing the case is a four step model for case analysis developed and practiced in Medical University – Pleven.

In Belgium the conditions that allow performing child euthanasia are: the child must have terminal illness with pain and suffering, expressed wish from the patient, approval from patient’s parents and the physician must prove that the child has the ability for rational decision-making. How can we prove that a child can make rational decisions? Most legislations around the world treat children as *legally incompetent*. It appears that professionals in Belgium generate some kind of autonomy to children. But how far does this autonomy goes if the child is terminally ill? Most bioethicists would argue that we should limit it because terminal diseases can influence our decision-making abilities. Justice also is a problem: do parents have the right to choose euthanasia for their child? Do patients have the right to die? Last but not least, beneficence and non-maleficence, who actually benefits from this new legislation: patients or their family? Many people want euthanasia because they want to get off their family’s shoulders. Do we apply this concept to terminally ill children? The Netherlands work towards patient beneficence. Not only that they try to investigate end-of-life decisions for children between the ages of 1 and 12 but they could open a clinic for child euthanasia. If they succeed this could be an interesting development in palliative care.

So far there are only few requests for child euthanasia in Belgium. In the Netherlands for a ten year period there were 5 cases for child euthanasia. Although there are not many cases for child euthanasia we should rethink our understanding of autonomy and justice when it comes to end-of-life care.

Palliative sedation for terminally ill patients

Assoc. Prof. Dr. Nikolai Yordanov, MD, PhD, COC-Vratsa,

Department “Medical and Social Sciences”; Affiliation “prof. Ivan Mitev”- Vratsa; MU- Sofia

Introduction: Bulgarian Law on Health clearly provides the right of palliative care for every Bulgarian citizen with advanced disease and poor prognosis and prohibits euthanasia in the country. Palliative care is specialized medical care aimed to reduce suffering of patients with advanced disease by relieving pain and other symptoms, and to offer support to patients and their families in attempts to provide maximum physical, mental and spiritual comfort.

In 2020 more than two thirds of deaths in Western society will be from chronic diseases, which means that the process of dying should be a long and often accompanied by unpleasant symptoms. Palliative sedation should be used in order to achieve maximum control over the symptoms in these final days. Palliative sedation (PS) is the use of (a) pharmacological agent(s) to reduce consciousness for treatment of intolerable and refractory symptoms. However, the application of PS raises a number of ethical concerns as “Isn’t PS a form of euthanasia?” PS differs from euthanasia and / or medically assisted suicide (MAS) by their main aim - to relieve symptoms and reduce the suffering of the patient, not to terminate patient’s life (patient’s death) as is the main goal of euthanasia and MAS. The main differences are:

	Palliative sedation and analgesia	Medically assisted suicide	Euthanasia
Death reason	Underlying disease (!!! possible double effect)	Intervention - prescribed by a doctor, but administered by the patient	Intervention - Performed by doctor
Intent /aim of the intervention	Symptoms relief	Termination of patient’s life	Termination of patient’s life
Legal?	Yes	No (legal in Swiss)	No (legal In some EU)

Material and methods: We present a clinical case of a terminal lung cancer patient with multiple brain metastases, with difficult to control symptoms as pain, dyspnea and seizures that required palliative sedation in order to provide symptomatic comfort.

Discussion: With the development of medical science more acute diseases are transformed into chronic, which significantly changes the characteristic of the last days of life of patients. These changes will require the application of still uncommon for our medical community methods for symptom control as palliative sedation, often with possible double effect – development of unwanted effect because of good intentions.

Conclusion: Palliative sedation aim is to relieve suffering neither to extend patient’s life nor to hasten his/her death. Palliative sedation is a method that helps to preserve human dignity by achieving maximal symptomatic control terminal patients.

15:30 – 15:45 Coffee break

15:45 – 17:30 ORAL PRESENTATIONS

Moderators: *Dr Els Maeckelberghe and Prof. Dr Silviya Yankulovska*

Respect for autonomy against hospitals guidelines

Prabesh Angbuhang, medical student 5th year, MU-Pleven

This report aims at presenting and discussing a case study of 11 year old patient who have been left with brain damage after hospital ignored the advice of his mother. The patient was born with congenital heart defect and cleft lip and had a history of numerous operations. Following a routine surgery at children's hospital, he was discharged but later developed complication. He was then taken back to children's hospital where the blood test showed he had anemia and required blood transfusion and infusion of heparin. However due to lack of beds, he was admitted to his local hospital and heparin was given following instruction from children's hospital. Their main concern at this point was to protect his artificial valves. Despite several protests from the mother about the risk of damaging vital organs, heparin was given. Following administration of heparin child suffered cardiac arrest and it took nearly 45 minutes to restart his heart by the resuscitation team. As a consequence of severe brain damage child is left quadriplegic and cannot talk requiring constant care.

Some of the points of discussion would be respect for autonomy of a mother against doctors working under the guidelines of Hospital protocol. In this case mother is the child's representatives and her respect for autonomy has been ignored. As a result massive burden lies on her in raising the child who needs constant care. On the other hand hospital had given priority to beneficence and non maleficence overruling her decision of respect for autonomy. Are the doctors to be blamed for their negligence?

Keywords: Anemia, heparin, brain damage and quadriplegic.

Managing Ethically Related Issues in Everyday General Practice

Hania Abbasi, medical student 6th year, MU-Pleven

Ethical issues are a mainstay in the medical field however in the realm of the media it is becoming more and more prevalent with headlines on many different ethical dilemmas or situations being shown to the general public. As future medical professionals and anyone related to the management or care of a patient, it is vital that there is a guided route of dealing with ethical related issues within the healthcare environment as whole and in my case specifically focusing on the field of General Practice. Using readily available sources, we can aim to form some sort of algorithm with which an adequate and all-rounded approach can be made. Issues will vary in their uniqueness case by case but by having an overall framework I aim to tackle the ambiguity to forming decisions on ethical cases within consultations we face in our everyday environment.

Some may argue that amongst the vast branches of medicine, the field of General Practice requires the most in depth patient communication and contact and hence is open to many different elements of ethical dilemmas. Common key pitfalls mean that it is easy for a newly qualified doctor to find dealing with ethical issues extremely problematic and so I believe it is of utmost importance that this framework is applied to a medical practitioner within a minimum of five years post-graduation till they become acquainted with, and gain vital experience in dealing with the array of ethical issues one faces in the General Practice environment.

The key elements needed for this algorithm can be drawn up in an 'ABCDEF' fashion with the basic tools of Autonomy, Beneficence, Confidentiality, Do not harm (Non-maleficence), Equality and Fairness (Justice). Furthermore, the ethical guidelines from individual countries e.g. 'BMA Handbook of Ethics & Good Medical Practice for GP's' are a cornerstone for coming to grips with ethical situations and how to deal with them. Coupling these with reflection; a key way to maintain good medical practice, one can form a strong basis to help in minimising challenging ethical conflicts.

Additions: Ethical Cycle; Step by Step approach according to Dr Rhona Knight GP member of RCGP Ethics Committee

Distinct Ethical Challenges Surrounding Surgery: Surgical Innovation, Surgical Teaching and the role of a Surgeon in the Balance of Patient Care

Syed Mohsin Hussain, medical student 6th year, MU-Pleven

Many professionals within the healthcare setting as well as the general population hold a stigma that ethics is somewhat insignificant within the surgical field compared with other specialties. This however is a gross misunderstanding as the ethics of surgical practice is a linchpin in providing an all-rounded, thorough care package to the patient.

Ethical dilemmas are numerous and occur on a case by case scenario for a surgical patient and there are specific rules and guidelines for surgical intervention because of the nature of the invasiveness. I aim to anchor my analysis around three major areas woven into the surgical field: innovation, teaching and the role of a surgeon in balancing patient care.

Primarily; due to the relentless progression of technology, constant modernisation in surgical techniques and innovation is routine. This is generally aimed at minimising patient recovery times as well as increasing effectiveness of treatment. Nonetheless, this poses an issue where there will always be a moment where the surgeon will be performing that specific technique for the *first time* on a real patient. Secondly, surgical teaching is of chief significance for budding surgeons to gain skills and experience under their belt. Experience and expertise in surgery is exceedingly valuable, as many operations are multi-faceted and complicated beyond expectation. If managed incorrectly, this can pose a predicament, where the surgeon may be performing the actual surgery either alone for the first time or dealing with a larger responsibility than they can handle. Finally, the aspect of the surgeons role in balancing patient care is becoming more and more of a potent issue due to prevailing privatisation of areas within medicine and this conflicting with the surgeon's treatment plans.

Henceforth I believe that having a firm understanding of these principles, one can either gain confidence in pursuing a career in surgery or become acquainted with issues faced by fellow colleagues within the surgical field of medicine.

Ethical Issues in Genome Editing using CRISPR/Cas9 System

Ammad Fouzi, medical student 3^d year and Azka Fouzi, medical student 4th year, MU-Pleven

Molecular biologists have been eagerly looking for cellular repair process to intervene and modify DNA of organisms. By introducing a new function or correcting a mutation in organism genome. In the past couple of years CRISPR/CAS9 has been the preferred method of genome editing due to its precision, low cost and simple construction. The system can introduce DNA in the germline of any organism, and modify somatic cells by genomic editing.

On paper this makes it very attractive for molecular biology labs all around the world but the problem lies in the regulation of its use. And this is what I have decided to do my research on. I will be discussing the advantages of using this modern invention as well as the setbacks. I will also be focusing on the ethical issues presented by this innovative technology in today's bioethical environment.

Ethical Issues:

Balance of risks and benefits:

Need to put more importance on potential risks such as off target mutations that damage organisms and environment.

Ecological Disequilibrium:

The possibility of mutations increases with every generation, may eventually lead to the disappearance of a whole population

Regulations for Consumers:

The efficacy of this new technique to obtain precise genetic modifications will make it difficult to identify GM products in the market

Application to Human Germline:

Prohibition on intervening in the human germline by UNESCO in 1997

The influence of pharmaceutical companies on healthcare

Gurpreet Kaur and Jency Mathew, medical students 5th year, MU-Pleven

The role of pharmaceutical companies is to discover, produce, and market drugs for the use as medications. Before drugs are marketed they are approved by the Food and Drug administration as safe and effective. Pharmaceutical companies have evolved vastly over the years and the industry generates billions of dollars in a year, in 2015 the revenue was \$1 trillion US dollars. More than \$11 billion US dollars are spent each year on promotion and marketing of drugs, about a half of this is spent on the sales representatives.

Research has shown that when incentives and funding by pharmaceutical companies are provided to physicians, the chances of physicians prescribing these specific drugs are increased.

Many physicians believe that representatives are providing accurate information about the drugs but they also believe that the representatives prioritize product promotion above patient's welfare

Samples, continued medical education and conference travel funding are felt to exert more influence than promotional material

Research also shows that interactions with pharmaceutical representatives were found to impact the prescribing practice of residents and physicians in that of preference and rapid prescribing of new drugs and decreased prescribing of generic drugs.

However, meetings with pharmaceutical representatives may provide improved ability to identify the treatment for complicated illnesses and provide improved awareness, which would not have been possible otherwise so the approach is working for an over-all well being of patients.

Physicians and researchers should exercise judgement in situation like these which are complex and ensure their judgements are not compromised by the financial ties with the pharmaceutical companies due to the fact that patients and the public place their trust in the decisions and judgement made.