



7th conference, Toulouse 25-27 September 2019
under the auspices of the Secretary General of the
Council of Europe, Mr Thorbjørn Jagland



COE-HELP WORKSHOP

The Council of Europe Programme for Human Rights Education for Legal Professionals (HELP) and Bioethics

26 September 2019

7th Conference of the European Association of Health law
Hotel Dieu St. Jacques, Toulouse (France)

PRESENTATION

The Council of Europe (CoE) Programme for Human Rights Education for Legal Professionals (HELP) aims at assisting mainly legal professionals, but also, where relevant, other categories of professionals, in effectively applying the European human rights standards in their daily work. This is done by developing and implementing high quality, tailor made online courses on various human rights related topics.

A CoE-HELP workshop will be organised within EAHL Toulouse conference, under the coordination of Ana Medarska-Lazova, HELP Project Officer and Katrin Uerpmann, Bioethics Unit.

This workshop will focus on HELP courses related to key human rights principles to be applied in the field of biomedicine that have been developed with the CoE Bioethics Unit.

After an introduction of HELP courses and methodology in bioethics sector, an overview will be provided of the key human rights principles dealing with e.g. free and informed consent, medical confidentiality and protection of health-related data. Further, their application in specific contexts will be analysed (e. g. biomedical research and genetic tests). Data protection and privacy rights will be finally addressed, focusing on health-related issues.

Some practical cases will be presented to explain how to assess their compliance with the relevant legal obligations. References to relevant jurisprudence of the European Court of Human Rights and of the Court of Justice of the European Union will be brought into discussion.



AGENDA

Coordinators

Ana Medarska-Lazova, HELP Project Officer, CoE

Katrin Uerpmann, Administrator, Bioethics Unit, CoE

Chairman

Laurence Lwoff, Head of Bioethics Unit, CoE

Annagrazia Altavilla, European Association of Health Law Board of Directors – France Representative - Espace de Réflexion Ethique PACA-Corse

INTRODUCTION

HELP courses and the HELP Methodology : HELP courses developed jointly by the CoE Bioethics and HELP Units

Ana Medarska-Lazova (HELP Unit, CoE)

COURSES

Key human rights principles in Biomedicine I (Introduction)

Ivana Roagna, Attorney, Human Rights trainer, Asti – (Italy)

Key human rights principles in Biomedicine II (Free and Informed Consent, Medical Confidentiality)

Katrin Uerpmann (Bioethics Unit, CoE)

The application of key human rights principles in Biomedicine in specific contexts (Biomedical research and genetic tests)

Fabio Macioce, Professor of Legal Theory and Bioethics, LUMSA University, Rome – (Italy)

Data Protection and Privacy Rights

Raluca Bercea, PhD, Lecturer at the Faculty of Law, Timisoara University – (Romania)

Debate & Final remarks

SPEAKERS' LIST

ANNAGRAZIA ALTAVILLA



Lawyer and former Professor at Aix-Marseille University, Annagrazia ALTAVILLA is responsible of International Relations of Espace Éthique PACA-Corse (Bioethics Research Centre AP-HM/Aix-Marseille University – France). As French representative in the board of Directors of the European Association of Health Law, she is also co-organizer of the 7th EAHL Conference.

As legal advisor and researcher, she has developed a long-standing experience in the field of Health Law and Bioethics. Annagrazia ALTAVILLA is expert/legal advisor of several EU/IMI founded projects.

As expert in ethics and patient rights, she was appointed by the European Commission as member of the European Medicine Agency (EMA) Paediatric Committee for three years. She was also member of the (EMA) Working Group for Third Countries Clinical Trials, as well as rapporteur of the *“Reflection paper on ethical and GCP aspects of clinical trials conducted outside of the EU/EEA”*.

Annagrazia ALTAVILLA is author of a book and about 50 publications in national and international journals. Speaker invited in more than 60 conferences in 15 countries as well as in European Institutions (European Commission, European Parliament, European Medicine Agency, Council of Europe), she has also lectured in Italian, French, Spanish, Belgium and Polish universities. She was member of the scientific/organization committees of several international conferences and courses and of the European School in Health Law and Bioethics (2006-2016).

After having obtained LL.M in Health Law in Italy and in France she was awarded a PhD in Sciences of Life and Health /Ethics (Robert Schuman Foundation fellowship) and an HDR (*“Habilitation à Diriger les Recherches »*) in France. She completed her education by an Executive Programme on Negotiations at Harvard Law School.

RALUCA BERCEA



Raluca BERCEA is a Romanian law professor at the Law Faculty in Timisoara, a lawyer and a training expert of the Council of Europe. Her research mainly focuses on European Union law and the Theory of Legal Comparison.

Since 2017, she is a trainer in the European Law of Human Rights of the Council of Europe, and since 2016 a representative of the Romanian National Union of Bars Association in the Council of Europe's *“HELP”* training department.

As a training expert of the Council of Europe, she has held continuous professional training programs for magistrates and lawyers in the fields of data protection anti-discrimination.



LAURENCE LWOFF



Laurence LWOFF holds a MSc. in reproductive physiology from the University of Paris VI – Jussieu (France).

She then obtained her degree in agronomy from the Institut National Agronomique Paris-Grignon (France) in 1986 and received her PhD in molecular biology in 1989.

She joined the Council of Europe in 1991, where she was entrusted with the responsibilities of the Secretariat of the Conventions concerning the use of animals in agriculture and science, in the Directorate of Legal Affairs. In 1999, her responsibilities were extended to biotechnology. She was the Secretary of the International Conference of the Council of Europe on Ethical Issues Arising from the Applications of Biotechnology (Oviedo, Spain, May 1999). In 2002, she joined the Bioethics Department where she has been responsible in particular for the activities on human genetics and on the protection of the human embryo and the foetus. She was the Secretary of the Group in charge of the elaboration of the Additional Protocol to the Convention on Human Rights and Biomedicine, concerning Genetic Testing for Health Purposes.

Since 2012, she is the Head of Bioethics Unit in the Human Rights Directorate, and Secretary of the Committee on Bioethics (DH-BIO), intergovernmental committee in charge of the activities on the protection of human rights in the biomedical field, at the Council of Europe.

FABIO MACIOCE



Fabio Macioce is full professor of Legal Theory and Bioethics at the Lumsa University of Rome.

His research interests focus on immigration and social integration, multiculturalism, group rights and individual rights, bioethics, law and religion and discursive ethics and law.

Professor Macioce spent research periods as a visiting scholar at the Centre for Socio-Legal Studies, University of Oxford (2014), as a visiting professor at the Facultad de Derecho, Universidad de Valencia (2017) and as faculty visitor at the Centre for Law, Medicine and Life Sciences, Cambridge University (2018).

As a certified trainer in the Council of Europe's HELP Training Methodology, Professor Macioce co-authored the HELP Course on Bioethics and co-tutored its first cross-border launch in the beginning of 2019.



ANA MEDARSKA-LAZOVA



Ana MEDARSKA-LAZOVA has been working at the Council of Europe HELP Secretariat since February 2019. She is involved in the development and implementation of a series of HELP courses, including the course on Key human rights principles in Biomedicine.

Before that, she worked at the Registry of the European Court of Human Rights as a case-processing lawyer (2012-2016).

Part of her previous background involves project management and working in civil society on human rights issues.

She is a lawyer, with a Master of Laws in Human Rights.

IVANA ROAGNA



Ivana Roagna is a practising criminal defence attorney and immigration lawyer and a Human Rights/Rule of Law Expert with 22 years of professional experience. She worked at the European Court of Human Rights and served as officer for the Council of Europe (CoE) in Strasbourg and Kosovo and for the OSCE Mission to Bosnia Herzegovina.

Ivana has advised the CoE, the International Organization for Migration (IOM), the OSCE Office for Democratic Institutions and Human Rights (ODHIR), the United Nations Interregional Crime and Justice Research Institute (UNICRI) and the Embassy of Italy to Afghanistan on a range of human-rights related issues such as independence of the judiciary, trafficking in persons, witness protection and International Criminal Law. She also produced expert's opinions and legislative expertises related to Moldova, Turkey, Ukraine, Italy.

Mainly at the request of the Council of Europe, Ivana has provided extensive human rights training for lawyers, judges, prosecutors, police officers and NGO activists in South-East Europe and the Caucasus and has been actively engaged in on-line education, contributing to a variety of courses currently available on the CoE's HELP platform.

As Senior Training Specialist at the UNICRI, she has developed training curricula and trained in Human Rights Law and European Standards professionals coming from Italy, Egypt, Brazil and Angola as well as members of UN and EU peacekeeping operations.



KATRIN UERPMANN



Following her law studies in Germany, Katrin UERPMANN started her career as a civil court judge in Berlin. During this time, she was also seconded to the German Federal Constitutional Court where she was the personal assistant of the President of that Court.

In 2004, Katrin joined the Registry of the European Court of Human Rights, where she worked as a case-lawyer, also preparing several cases relating to bioethical questions for consideration by the Grand Chamber of that Court.

She joined the Secretariat of the Council of Europe's Committee on Bioethics in 2015.