

COUNCIL OF EUROPE



CONSEIL DE L'EUROPE

Strasbourg, 8 November 2017

DH-BIO/abr RAP 12

COMMITTEE ON BIOETHICS

(DH-BIO)

12th MEETING

Strasbourg, 24-27 October 2017

ABRIDGED REPORT

I. Adoption of the agenda

1. The Committee on Bioethics (DH-BIO) held its 12th meeting in Strasbourg from 24 to 27 October 2017. The agenda of the meeting and the list of participants appear in Appendix I and Appendix II to this report.
2. On 24-25 October, the International Conference “20th anniversary of the Oviedo Convention: relevance and challenges” was held under the auspices of the Czech Chairmanship of the Committee of Ministers of the Council of Europe. The programme of the conference appears in Appendix III to this report. The video recording of the conference is available on line: www.coe.int/bioethics.
3. On 26 October, the DH-BIO held an exchange with the European Group on Ethics in Science and New Technologies (EGE) on the basis of the outcome of the Conference marking the 20th anniversary of the Oviedo Convention. It was agreed to consider way(s) to continue the dialogue between the EGE and the DH-BIO.

II. Chart of signatures and ratifications of the Convention on Human Rights and Biomedicine, the Protocol on the Prohibition of Cloning Human Beings, the Protocol concerning Transplantation of Organs and Tissues of Human Origin, the Protocol concerning Biomedical Research and the Protocol concerning Genetic Testing for Health Purposes

4. On 24 October 2017, in the presence of the DH-BIO, the Permanent Representative of the Czech Republic to the Council of Europe, Ambassador Emil Ruffer, together with the Deputy Secretary General of the Council of Europe, signed the Additional Protocol to the Convention on Human Rights and Biomedicine concerning Genetic Testing for Health Purposes (CETS 203).

III. Developments in the field of bioethics

5. The DH-BIO took note of the developments in the field of bioethics within the member states, as well as in international organisations. It also took note of the relevant developments in other Council of Europe bodies.

IV. Additional Protocol on the protection of the human rights and dignity of persons with mental disorder with regard to involuntary placement and involuntary treatment

6. The DH-BIO examined the draft Additional Protocol with change proposals and elements for the Draft Explanatory report prepared by the Secretariat in consultation with the Bureau, on the basis of the comments submitted by delegations.
7. A number of changes were introduced to the draft Protocol until chapter IV included. Lack of time prevented the Committee from finalising its examination of the draft. The Secretariat would send out the draft as revised to delegations.
8. The Secretariat would revise the Draft Explanatory Report with a view to sending it to Delegations for comments.
9. The DH-BIO confirmed that further elaboration of the draft Protocol should continue between plenary meetings at the level of delegations. To these ends, a consultation meeting would take place in early 2018.

10. The DH-BIO had already agreed on sending the draft protocol, when considered appropriate, for opinion to CDDH and CPT. It was proposed to extend the invitation to give an opinion on the draft Protocol to the Ad Hoc Committee for the Rights of Persons with Disability (CAHDPH), the Parliamentary Assembly (PACE) and to the CoE Commissioner for Human Rights. Consideration could be given to the possibility to send the draft Protocol for opinion, together with its draft Explanatory Report, after the 13th DH-BIO.
11. **Delegations were invited to send any additional written comments to those already sent, on the draft Protocol, together with drafting proposals, by 6 December 2017.**

V. Prohibition of financial gain

12. The DH-BIO examined the Draft Guide for the implementation of the Principle of Prohibition of Financial Gain as revised by the Bureau in the light of the comments made by delegations.
13. The DH-BIO agreed on a number of, mainly editorial, changes to the document.
14. In the absence of quorum, the DH-BIO could not formally adopt the document. It nevertheless held an indicative vote (26 in favour, 1 against, no abstention). On that basis, it agreed to adopt the document via written procedure.
15. **The Secretariat would send the text as finalised to delegations. The delegations will be invited to indicate whether they vote in favour of/against the adoption of the Guide or abstain, by 4 December 2017.**
16. Subject to the adoption of the Guide, it would then be sent to the CD-P-TO and the CD-P-TS inviting these committees to also adopt the text.

VI. Working methods and future activities of the DH-BIO

Public Debate

17. The Chair of the Ad-Hoc Group on public debate informed the DH-BIO about the working plan of the Group. She mentioned that the Group, currently composed of three members, could benefit from participation of another person with expertise or practical experience in the organization of public debate. **Delegations were invited to make proposals.**

Gene Editing

18. The DH-BIO agreed that the Bureau, in cooperation with the Secretariat and in consultation with the Rapporteur on genetics and genomics, would prepare questions in relation to Article 13 of the Oviedo Convention to be sent to delegations by early December 2017, in view of initiating the examination on the ethical and legal challenges raised by these new genome editing technologies, as agreed in the DH-BIO Statement adopted in December 2015.

Strategic Action Plan

19. The DH-BIO agreed with the Bureau proposal to set up a group entrusted with drafting responsibility for the elaboration of a Strategic Action Plan aimed at defining the main axes and objectives of the work of DH-BIO in the next few years, where appropriate in cooperation with other committee and/or intergovernmental organisations, to address key human rights challenges raised by developments in the biomedical field. Subject to their acceptance, the group would be composed of the conference rapporteurs (Ms

Isabelle Erny, Ms Anne Forus, Ms Tina Garanis-Papadatos, Prof. Stefano Semplici and Prof. Constantinos Phellas), the Chair of the conference preparatory Group, Prof. Zvonko Magic, and Prof. Givi Javashvili as Bureau member. The general rapporteur Dr Siobhan O'Sullivan would be invited to chair the group.

20. The Group would be asked to base its work on the outcome of the Conference, the preparatory studies, the outcome of the high level seminar on international case law and the replies submitted by Delegations, as well as national and international bodies, to the questionnaire on the Oviedo Convention and related legal instruments, their relevance and challenges.

Classification of documents

21. Taking into account the principle of transparency as well as the sensitivity of the issues addressed, the DH-BIO agreed with the proposal of the Bureau for the classification of its documents, in the light of Res (2001)6 of the Committee of Ministers.

VII. Bureau Elections

22. The DH-BIO re-elected by acclamation Dr Beatrice Ioan (Romania) as its Chair and Ms Tesi Aschan (Sweden) as its Vice-Chair for a new one year term.

VIII. Dates of next meetings

23. The DH-BIO agreed on the following dates for its next meetings:
 - **13th meeting of the DH-BIO: 22-25 May 2018** (to be organised in Cyprus, at the invitation of the Cyprus authorities)
 - **14th meeting of the DH-BIO: 20-23 November 2018**, in Strasbourg.

IX. Other business


PACE Rec 2115 (2017) “The use of new genetic technologies in human beings”
PACE Rec 2116 (2017) “Promoting the human rights and eliminating discrimination against intersex people”

24. At its 1298th meeting at Deputies level, the Committee of Ministers had agreed to communicate the Recommendation 2115 (2017) and Recommendation 2116 (2017) of the PACE to the Steering Committee for Human Rights (CDDH) and to the Committee on Bioethics (DH-BIO), for information and possible comments by 12 December 2017.
25. Following this decision, **delegations were invited to send possible remarks on the draft comments prepared by the Secretariat on the above mentioned PACE Recommendations by 10 November 2017.** The Bureau was entrusted with finalising the comments in the light of the remarks received with a view to send them to the Committee of Ministers by 12 December 2017.

APPENDIX I
Agenda of the 12th meeting of the DH-BIO

LIST OF ITEMS

1. Adoption of the draft agenda
2. Prohibition of financial gain
3. Additional Protocol on the protection of the human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment
4. Working methods and future activities of the DH-BIO
5. Cooperation activities
6. Bureau elections
7. Dates of the next meetings
8. Other business
9. Decisions taken by the DH-BIO at its 12th meeting

 Points for information *

10. Chart of signatures and ratifications of the Convention on Human Rights and Biomedicine, the Protocol on the Prohibition of Cloning Human Beings, the Protocol concerning Transplantation of Organs and Tissues of Human Origin, the Protocol concerning Biomedical Research and the Protocol concerning Genetic Testing for Health Purposes
11. Developments in the field of bioethics
12. Cooperation with other committees

*Taking into account the limited time for discussion and priority set for this two days plenary session, these points will only be dealt with in writing.

TUESDAY 24 – WEDNESDAY 25 OCTOBER

**International conference
“20th anniversary of the Oviedo Convention: relevance and challenges”**

THURSDAY 26 OCTOBER (9.00 – 18.00)

9.00 – 10.30	Joint session with the European Group on Ethics in Science and New Technologies Exchange of views on the outcome of the conference
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Coffee break

11.00	1. Adoption of the draft agenda
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11.10	2. Prohibition of financial gain - Examination of the draft Guide as editorially revised by the Bureau with a view to its <u>adoption</u> .
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13.00 Lunch break

14.30	2. Prohibition of financial gain (to continue)
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4. Working methods and future activities of the DH-BIO



- a. Priorities in 2018-2019
- b. Strategic Action Plan: working method for its development
- c. Classification of documents

5. Cooperation activities

- *Seminar on ethical and legal aspects of informed consent held in Moscow, June 2017*
- Request for seminar on end-of-life situations by the Cypriote authorities (June 2018)
- Cooperation activities within the framework of the Council of Europe Action plan for Belarus 2016-2017

FRIDAY 27 OCTOBER (9.00 – 13.30)

9.00	3. Additional Protocol on the protection of the human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment - Examination of the proposals for the revision of the draft Additional Protocol and its draft Explanatory Report, in the light of the comments received by delegations - Next steps to be considered: <ul style="list-style-type: none"> o Consultation meeting with delegations concerned o Request for opinion on the draft Protocol from other Council of Europe Committees
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	<p>6. Bureau elections Delegations are invited to proceed to the election of the Chair and Vice Chair for a one year term. Submission for nominations should be sent in writing to the Secretariat by <u>14.00 on Thursday 26 October 2017.</u></p>
	<p>7. Dates of the next meetings Dates proposed:</p> <ul style="list-style-type: none"> - 13th meeting of the DH-BIO: 21-24 May 2018 (alternative 4-8 June 2018) in Cyprus - 14th meeting of the DH-BIO: 20-23 November 2018 (alternative 6-9 November 2018)
	<p>8. Other business</p>
	<p>9. Decisions taken by the DH-BIO at its 12th meeting - Approval of the list of decisions</p>
<p>POINTS FOR INFORMATION (Not to be discussed. Exchange of information in writing only)</p>	
	<p>10. Chart of signatures and ratifications of the Convention on Human Rights and Biomedicine, the Protocol on the Prohibition of Cloning Human Beings, the Protocol concerning Transplantation of Organs and Tissues of Human Origin, the Protocol concerning Biomedical Research and the Protocol concerning Genetic Testing for Health Purposes</p>
	<p>11. Developments in the field of bioethics Delegations, including observers, are invited to send information in writing.</p> <ol style="list-style-type: none"> a. Developments in member states and other states b. Developments in the field of bioethics in international organisations c. Relations with other international organisations: list of meetings d. Developments in other Council of Europe bodies e. Developments at the European Court of Human Rights
	<p>12. Cooperation with other committees</p> <ol style="list-style-type: none"> a. European Committee on Organ Transplantation (CD-P-TO) b. European Committee on Blood Transfusion (CD-P-TS) c. Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD)

APPENDIX II List of participants

MEMBER STATES / ETATS MEMBRES

Albania/Albanie -

apologised/excusé

Andorra/Andorre – Mme Imma RODRIGUEZ, BATLLIA D'ANDORRA, Av. Tarragona, Ed. Les Columnes 62, Andorra, la Vella, AD 500 PRINCIPAUTÉ D'ANDORRE

Armenia/Arménie – Mr Igor MADOYAN, Phd, President of National Center of Bioethics, n.24, ave Sayat-Nova, apt. 14, entrance 1, 0001 YEREVAN

Austria/Autriche – Dr Renate FALLY-KAUSEK, Medical Officer, Federal Ministry of Health, Department III/8– Health of children and young people, gender aspects, nutrition, Radetzkystrasse 2, A-1030 WIEN

Mag. Martina ERLEBACH, juge, référendaire de la section civile, droit national de la famille, département I 1, 1070 Vienne, Museumstraße 7

Ms. Patrizia D'ACERNO, Austrian Bioethics Commission, Ballhausplatz 2, 1010 Wien

apologised/excusée

Azerbaijan/Azerbaïdjan – Dr. Gulnara BALAKISHIYEVA, Ph.D. in molecular biology, Senior Researcher at Department of Fundamental Problems of Biological Productivity, Institute of Molecular Biology and Biotechnology, Azerbaijan National Academy of Sciences, 2a Matbuat avenue, Az-1073, Baku

Belgium/Belgique – Mme Régine WILMOTTE, Juriste au sein de la direction générale des Etablissements de Soins du Service public fédéral « Santé publique », Place Victor Horta 40, boîte 10, 1060 Bruxelles

Bosnia and Herzegovina/Bosnie-Herzégovine – Dunja ŠMITRAN, Ministry of Civil Affairs of Bosnia and Herzegovina, Trg BiH 1, 71000 Sarajevo

apologised/excusée

Dalibor PEJOVIC, Head of Unit for Statistics and Analytical Affairs and Reporting in Health, Department for Health

Bulgaria/Bulgarie – Ms Sylvia TOMOVA, Ministry of Health, Legal Directorate, Chief Legal Advisor, Place St Nedelia 5, Sofia 1000

Croatia/Croatie – Dr. Vanja NIKOLAC, Head of Service, Service for blood, tissues and cells inspection, Ministry of Health, Ksaver 200a, 10 000 Zagreb

Cyprus/Chypre – Prof. Constantinos N. PHELLAS, Chair of the Cyprus National Bioethics Committee, University of Nicosia, 46, Makedonitissas Ave. P.O. Box 24005, 1700 Nicosia

Czech Republic/République Tchèque – Prof. Pavel MARTASEK, Professor of Medicine, Expert on Genetics, Dept. of Pediatrics, Center for Applied Genomics, 1st School of Medicine, Charles University, Ke Karlovu 2, Building D /2nd floor, 128 08 PRAGUE 2

Denmark/Danemark – Emilie SORENSEN, The Ministry of Health, Holbergsgade 6, Copenhagen

Estonia/Estonie – Prof. Hele EVERAUS, Head of the Clinic, Haematology and Oncology Clinic, Tartu University, Tartu University Hospital, Puusepa 8, 51014 Tartu

Finland/Finlande – Ms Ritva HALILA, M.D., Ph.D., docent, Senior Medical Officer, General Secretary, National Advisory Board on Social Welfare and Health Care Ethics (ETENE), Ministry of Social Affairs and Health, P.O. Box 33 (Meritullinkatu 10), FI-00023 Government

Ms Katja FOKIN, Legal Officer, Unit for Human Rights Courts and Conventions, Legal Service, Ministry of Foreign Affairs

France – Mme Marie-Aude RECHER, Bureau du droit des personnes et de la famille (C1), Direction des affaires civiles et du Sceau, Ministère de la Justice

Mme Isabelle ERNY, Attachée principale d'administration centrale, Ministère de la Santé, Direction Générale de la Santé, Secrétariat Général, Division droit, éthique et appui juridique, 14 avenue Duquesne, 75350 PARIS 07 SP

Mme Marie-Noémie PRIVET, Ministère des affaires étrangères et du développement international, Direction des affaires juridiques, Sous-direction des droits de l'Homme, 57, bd des Invalides, 75007 PARIS

Dr Jacques MONTAGUT, Directeur de l'IFREARES, 20 route de Revel, 31400 TOULOUSE

Georgia/Géorgie – Dr Givi JAVASHVILI, Head of Family Medicine Department, State Medical Academy of Georgia, Chairman of the National Council on Bioethics, 29 I. Chachavadze Avenue, 0179 TBILISI

Germany/Allemagne – Jan WITZMANN, Division III B 6, Insurance Law; IOPC-Funds; UNCITRAL, Federal Ministry of Justice and Consumer Protection, Mohrenstraße 37, 11015 Berlin

Prof. Dr. Elmar DOPPELFELD (Honorary chair of the "Permanent Working Party of Research Ethics Committees in Germany Inc."), Lenaustraße 15, D-50858 Köln

Prof. Dr. Dr. Thomas HEINEMANN, Philosophical-Theological University of Vallendar (PTHV), Pallottistraße 3, D-56179 Vallendar

Dr. Ingo HÄRTEL, Federal Ministry of Health, Division 317, Friedrichstraße 108, D-10117 Berlin

Dr. Stefan OSSEGE, Federal Ministry of Education and Research, Division 612, Friedrichstraße 130 B, D-10117 Berlin

Greece/Grèce – Dr Stamatia GARANIS-PAPADATOS, Lecturer, National School of Public Health, 196 Alexandras Avenue, 11521 Athens

Dr Foteini A. TZAVELLA, PhD, Assistant Professor of Health Sociology, Department of Nursing, University of Peloponnese, Efstathiou and Stamatikis Valiotti & Plateon str., Sparta 231 00

Hungary/Hongrie - Ms Eszter MAROSI, Head of Secretariat, Medical Research Council, H-1051 Budapest, Arany János utca 6-8. 3/334

Iceland/Islande – Ms. Thorunn STEINSDOTTIR, Legal Advisor, Ministry of Welfare, Hafnarhúsinu við Tryggvagötu, 101 Reykjavik

Ireland/Irlande – Mr Paul IVORY, Bioethics Officer, CMO's Office, Department of Health, Hawkins Street, Dublin 2 **apologised/excusé**

Italy/Italie - Laura PALAZZANI, Lumsa, Facoltà di giurisprudenza, via Pompeo Magno 22, 00192 Roma

Prof. Assunta MORRESI, Prof. Associato di Chimica Fisica, Dipartimento di Chimica, Biologia e Biotecnologie, Università degli Studi di Perugia, V. Elce di Sotto, 8, 06123 PERUGIA

Latvia/Lettonie – Dr.Vents SĪLIS, Assistant Professor at Riga Stradins University, Department of Humanities, Dzirciema street 16, Riga, LV- 1007

Liechtenstein

apologised/excusé

Lithuania/Lituanie – Dr Eugenijus GEFENAS, Chairman of Lithuanian Bioethics Committee, Associate Professor at Vilnius University, Lithuanian Bioethics Committee, Vilnius str.33, LT-2001 VILNIUS

Luxembourg – Mr Jean-Claude MILMEISTER, Chargé d'études, Diplômé en biologie et en bioéthique, Commission Consultative Nationale d'Éthique pour les Sciences de la Vie et de la Santé (C.N.E.), 18-20, montée de la Pétrusse, L-2327 Luxembourg **apologised/excusé**

Mr Mike SCHWEBAG, Médiateur Santé, Service national d'information et de médiation santé, 73, rue Adolphe Fischer (4e étage), L-1520 Luxembourg **apologised/excusé**

Malta/Malte - Prof. Pierre MALLIA, MD PhD, CBiol MPhil MA(Law) DipICGP MMCFD MRCP FRCGP, Professor of Family Medicine, Bioethics & Patients' Rights, Chairperson, National Health Ethics Committee, Dept. of Health, Chairperson, Bioethics Consultative Committee, Ministry of Health, Coordinator, Bioethics Research Programme, Univ. of Malta, President, Malta College of Family Doctors

Republic of Moldova/République de Moldova – Mr. Andrei ȘVEȚ, Head of the Legal Department, Ministry of Health

Monaco - **apologised/excusé**

Montenegro/Monténégro – Ms Olivera MILJANOVIC, Prim. doc., Director of the Centre for Medical Genetics and Immunology, Medical Centre of Montenegro, Krusevac bb, 81000 Podgorica

Netherlands/Pays-Bas – Ms. Joyce BROUWERS-VERSTAPPEN, (Senior) Beleidsmedewerker, Afdeling Ethiek, directie Publieke Gezondheid, Ministry of Health, Welfare and Sport, Parnassusplein 5, The Hague **apologised/excusée**

Mr Jim TERWIEL, Deputy head ethics department, Ministry of Health, Welfare and Sports, PO Box 20350, 2500EJ, The Hague **apologised/excusé**

Norway/Norvège – Mrs Anne FORUS, Senior Adviser, ph.d, Biotechnology and health legislation department, Division of specialised health care services, Norwegian Directorate of Health, P.O.Box 7000, St Olavs plass, N-0130 Oslo

Camilla Closs WALMANN, Senior Adviser, Department for Biotechnology and Health Law, Norwegian Directorate of Health, P.O.Box 7000 St Olavs plass, N-0130 Oslo

Vårin HELLEVIK, Norwegian Directorate of Health, Department of Specialized Mental health care and Addiction Treatment, Pb. 7000 St. Olavs plass, 0130 Oslo **apologised/excusée**

Poland/Pologne – Ms Mariola GROCHULSKA, Département des droits de l'homme, Ministère de la Justice, Al. Ujazdowskie 11, 00-950 WARSAW

Portugal - Prof. Miguel OLIVEIRA DA SILVA, Medical Ethics Full Teacher at Lisbon Faculty of Medicine Av. Prof. Egas Moniz 1640-028, Lisboa

Romania/Roumanie – Mrs Beatrice Gabriela IOAN, Associate Professor, President of the Bioethics Commission of the Romanian College of Physicians, Institutul de Medicina Legală, str. Bunavestire nr. 4, IASI

Mr. Gheorghe BORCEAN, President de L'Ordre des Medecins et Prof. Ass.a L'Universite de Medecine et Pharmacie " Victor Babes" de Timisoara, Vice-President of the Romanian College of Physicians, Spitalul Municipal Caransebes, str. Gradinilor nr. 36^a, CARANSEBES, jud. CARAS-SEVERIN 325400

Russian Federation/Fédération de Russie – Ms Irina NEKHAEVA, attachée, Department for the common European cooperation, MFA

San Marino/Saint-Marin - Dr. Luisa BORGIA, Vice-President of the National Ethics Committee, Contrada Le Grazie, n.3, 62029 Tolentino (MC), Italia

Serbia/Serbie - Prof. Dr Zvonko MAGIC, Head of the Institute for Medical Research in the MMA (Military Medical Academy), professor of the human genetics at the Medical Faculty and Cochairmen of the National Committee for bioethics of UNESCO Commission of Serbia, Serbian Academy of Sciences and Arts, 11000 Belgrade

Slovakia/Slovaquie – Assoc. Prof. Jozef GLASA, MD, PhD, PhD; Institute of Pharmacology and Clinical Pharmacology, Slovak Medical University; National Reference Centre for Management of Chronic Hepatitis; Institute of Medical Ethics and Bioethics n.f.*; Ethics Committee, Ministry of Health SR; Limbová 12, 83303 Bratislava

Slovenia/Slovénie – Prof. Marjeta TERČELJ ZORMAN, Dr.Med. Na Griču 14, Mlaka Pri Kranju,4000 Kranj

Urh GROSELJ, MD, MA, University Children's Hospital, University Medical Center Ljubljana, Bohoriceva 20, 1000 Ljubljana **apologised/excusé**

Spain/Espagne – M^a Concepción MARTIN ARRIBAS, Subdirección General de Investigación en Terapia Celular y Medicina Regenerativa – Instituto de Salud Carlos III – ISCIII, Avda. Monforte de Lemos 5, 28029 Madrid

Carlos ALONSO BEDATE, Centro de Biología Molecular, Member of the National Committee for Bioethics, C/ Alberto Aguilera, 21. 28015 Madrid

Prof. Carlos M. ROMEO – CASABONA, Professor of Penal Law, Head, Inter-University Chair in Law and the Human Genome, Avda. de las Universidades 24; 48007 BILBAO

Sweden/Suède – Mrs Tesi ASCHAN, Legal Adviser, The National Board of Health and Welfare, Socialstyrelsen, 106 30 Stockholm

Switzerland/Suisse – Mr Rodrigo RODRIGUEZ, Prof. dr en droit, avocat, Département fédéral de justice et police DFJP, Office fédéral de la Justice OFJ, Domaine de direction Droit privé, Bundesrain 20, 3003 Bern **apologised/excusé**

Dr Martin GÖTZ, Office fédérale de la santé publique, Division Biomédecine, collaborateur scientifique, Seilerstrasse 8, 3003 Bern

"The former Yugoslav Republic of Macedonia"/« L'ex-République yougoslave de Macédoine » - Ms. Evgenija ILIEVA Ph.D, Head of Department for Human Rights and NGO's, Ministry of Foreign Affairs of the Republic of Macedonia

Turkey/Turquie – Prof. Ergun ÖZSUNAY, Professor of Civil, Comparative Law and EU Private law, Istanbul Culture University, Faculty of Law, İstiklal cad. 245, Tunca Apt. Daire 7, 34430 ISTANBUL

Ukraine - Prof Zoreslava SHKIRYAK-NYZHNYK, Vice-president of Bioethics Committee of National Academy of Medical Sciences, Chief of the Department of Family Health Problems, Academy of Postgraduate Education, Institute of Paediatrics, Obstetrics and Gynaecology, Mayborody str., 8, 04050 KYIV

United Kingdom/Royaume-Uni - Dr Mark BALE, Deputy Director, Health Science & Bioethics Division, Department of Health, Richmond House, Whitehall, London SW1A 2NS

INVITED EXPERTS / EXPERTS INVITES

Elaine GADD, Honorary Professor, School of Law, Queen Mary University of London, Fox Court, 6 Brooke St, London, WC1X 8HN

Emmanuel Agius

Professor of philosophical and theological ethics at the University of Malta, the Dean of the Faculty of Theology and member of the EGE since 2005

Anne Cambon-Thomsen

Emeritus Research Director in CNRS (French national centre for scientific research), member of a joint research Unit on epidemiology and public health at Inserm (National Institute for Health and Medical Research) and University Toulouse III Paul Sabatier

Ana Sofia Carvalho

Professor of Bioethics and Director of the Institute of Bioethics, Catholic University of Portugal, and Chair of the Portuguese UNESCO Chair in Bioethics (2014-2017)

Eugenijus Gefenas

Professor and Director of the Department of Medical History and Ethics at the Medical Faculty of Vilnius University; Director of the Lithuanian Bioethics Committee

Julian Kinderlerer

Emeritus Professor of Intellectual Property Law at the University of Cape Town; elected President of the former EGE (2011 – 2016)

Andreas Kurtz

Biologist, Berlin-Brandenburg Center for Regenerative Therapies, Charité Universitätsmedizin Berlin; Head of the human pluripotent stem cell registry (since 2006)

Jonathan Montgomery

Professor of Health Care Law at University College London; Chair of the Health Research Authority in England; Chair Nuffield Council on Bioethics (2012-2017)

Herman Nys, Deputy Chair

apologised/excusé

Emeritus Professor in medical law at KU Leuven, editor-in-chief of the European Journal of Health Law and editor of the International Encyclopaedia of Medical Law. Member of the former EGE since 2011

Siobhán O'Sullivan, Deputy Chair

Lecturer in Health Care Ethics and Law, Royal College of Surgeons, and former Chief Bioethics Officer, Ministry of Health, Ireland. Member of the former EGE since 2011

Laura Palazzani

Professor of Philosophy of law and biolaw, Lumsa University in Rome, member of the UNESCO International Bioethics Committee, Vicechair of the Italian Committee for Bioethics and member of the former EGE since 2011

Barbara Prainsack

Professor at the Department of Global Health & Social Medicine at King's College London

Carlos Maria Romeo Casabona

Professor of Criminal Law; Director, Chair in Law and the Human Genome, University of the Basque Country. Member, Committee of Bioethics of Spain

Nils-Eric Sahlin

Professor of Medical Ethics, Lund University; member of The Royal Swedish Academy of Letters, History and Antiquities, Chairman of The Swedish Research Council's Expert Group on Ethics

Marcel Jeroen Van den Hoven

apologised/excusé

Professor of Ethics and Technology at the Delft University of Technology; founding Editor in Chief of Ethics and Information Technology

Christiane Woopen, Chair

Professor for Ethics and Theory of Medicine at the University of Cologne. Executive Director of the Cologne Center for Ethics, Rights, Economics, and Social Sciences of Health, member of the UNESCO International Bioethics Committee and former chair of the German Ethics Council

PARTICIPANTS

CDCJ – Mr Rodrigo RODRIGUEZ, Prof. dr en droit, avocat, Département fédéral de justice et police DFJP, Office fédéral de la Justice OFJ, Domaine de direction Droit privé, Bundesrain 20, 3003 Bern
apologised/excused

CDDH – Mme Brigitte KONZ, Juge de Paix directrice, Cité judiciaire, Plateau du St Esprit, Bâtiment JP - L-1475 Luxembourg

CD-P-TS – Dr. Guy RAUTMANN, Secretary of the European Committee on Blood Transfusion (CD-P-TS), European Directorate for the Quality of Medicines and HealthCare, Department of Biological Standardisation and OMCL Network

CD-P-TO – Ms Marta LOPEZ FRAGA, Secretary of the CD-P-TO
apologised/excused

T-PD – Ms. Sophie KWASNY, Administrator
apologised/excused

CAHDPH - Ms. Ita MIRIANASHVILI, Head of Section, Rights of persons with disabilities

CPT – Michael NEURAUTER, Head of Division of the Secretariat of CPT

PARLIAMENTARY ASSEMBLY/ASSEMBLÉE PARLEMENTAIRE – Ms Petra de SUTTER Member of the Committee on Social Affairs, Health and Sustainable Development/Membre de la Commission des questions sociales, de la santé et du développement durable, Member of the Parliament of Belgium

Ms Ayşegül ELVERİŞ, Secretary, Committee on Social Rights, Health and Sustainable Development

OFFICE OF THE COMMISSIONER FOR HUMAN RIGHTS / BUREAU DU COMMISSAIRE AUX DROITS DE L'HOMME - Mr Hasan BERMEK, Adviser, Council of Europe, F-67075 Strasbourg Cedex
apologised/excused

CONFERENCE OF INGOS/ CONFÉRENCE DES OING – Dr André CLAVERT, Docteur en Médecine, docteur d'Université, Membre de Médecins du Monde, Membre du CEERE Centre européen d'enseignement et de recherche en éthique, 22 rue Schwendi 67000 Strasbourg

OTHER PARTICIPANTS / AUTRES PARTICIPANTS

EUROPEAN COMMISSION/COMMISSION EUROPEENNE – Dr Jim DRATWA, Head of Ethics and Head of the EGE Secretariat, Member of the Bureau of European Policy Advisers (BEPA), European Commission, Rue de la Loi 200 Wetsraat, BERL 8/358, B-1049 Brussels

Mrs Barbara GIOVANELLI

Canada – Dr. Peter MONETTE, Manager of Bioethics, Department of Health Canada, Science Policy Directorate, Strategic Policy Branch, Health Canada, Brooke Claxton Building, 70 promenade Colombine Driveway, Tunney's Pasture, Ottawa, Ontario K1A 0K9 , Postal Locator: 0909C

apologised/excusé

Holy See/Saint-Siège – Mgr. Jacques SUAUDEAU, Cure Saint Bruno, 5 Place Saint Bruno, 38500 Voiron, France

Japan/Japon – Mr Takaaki SHINTAKU, Consul, Attorney Consulat Général du Japon à Strasbourg, 20, place des Halles, 67 000 STRASBOURG

apologised/excusé

Mexico/Mexique – Dr. Manuel H RUIZ DE CHÁVEZ, President of the Council of the National Commission of Bioethics. Calz. Arenal No. 134, Col. Arenal-Tepepan, Deleg. Tlalpan, Mexico D. F., Mexico

USA/Etats-Unis d'Amérique –

apologised/excusé

Belarus – Siarhei LIASHCHUK, Head of the National Transplant Registry, PhD, Semashko str.8 220045 Minsk Belarus

Valerya SOKOLCHIK - Dean of the Department of Public Health and Healthcare Management, Belarusian Medical Academy of Post-Graduate Education

UNESCO – Mrs. Dafna FEINHOLZ KLIP, Section de la bioéthique, Division de l'éthique des sciences et des technologies, UNESCO, 1 rue Miollis, 75732 PARIS CEDEX 15

OECD/OCDE – Mr David WINICKOFF, STI/STP

apologized/excusé

OBSERVERS / OBSERVATEURS

KEK – Conference of European Churches/Conférence des Eglises Européennes – Julija VIDOVIC, Conférence des Eglises européennes, 8, rue du Fossé des Treize, 67000 Strasbourg

INGO

Dr Régine ERNST - Project Manager on Rehabilitation and Foreign Affairs, Bundesarbeitsgemeinschaft für Rehabilitation e.V./Rehabilitation International (RI), Solmsstrasse 18, D-60486 Frankfurt am Main

apologised/excusée

Gemma HOPE, Head of Policy & Research, Shaw Trust (member of Rehabilitation International (RI))

J Patrick CLARKE, European Disability Forum (EDF), Square de Meeus 35, 1000 Brussels, Belgium

Jolijn SANTEGOEDS, European Disability Forum (EDF)

Alva FINN, European Disability Forum (EDF)

European Association of Service Providers for Persons with Disabilities (EASPD)

apologised/excusé

SECRETARIAT

**BIOETHICS UNIT
UNITE DE LA BIOETHIQUE**

Ms Laurence LWOFF, Secretary of the DH-BIO / Secrétaire du DH-BIO, Tel: +33 (0) 388 41 22 68, Email: laurence.lwoff@coe.int

Mr Ramon PRIETO SUAREZ, Administrator / Administrateur, Tel: +33 (0) 388 41 29 93, Email: ramon.prieto-suarez@coe.int

Ms Katrin UERPMANN, Administrator / Administratrice, Tel: +33 (0) 390 21 43 25, Email: katrin.uerpmann@coe.int

Ms Anna MIKHEDENKO, Project Officer / Chargée de projet, Tel: +33 (0) 390 21 60 49, Email: anna.mikhedenko@coe.int

Ms Tatiana WINTER, Assistant / Assistante, Tel: +33 (0) 388 41 33 67, Email: tatiana.winter@coe.int

Ms Catherine FORNÉ, Assistant / Assistante, Tel: +33 (0) 388 41 22 20, Email: catherine.forne@coe.int

Ms. Irene DOMENICI, Trainee / Stagiaire

INTERPRETERS / INTERPRETES

24-25/1/2017:

Corine McGEORGE
Christopher TYCZKA
Christine TRAPP

26-27/10/2017:

Amanda BEDDOWS
Christopher TYCZKA
Christine TRAPP

APPENDIX III
Programme of the Conference

TUESDAY 24 OCTOBER 2017

9.30 SESSION I - OPENING

Chair: *Mrs Beatrice Ioan (Romania), Chair of the Committee on Bioethics (DH-BIO) of the Council of Europe*

- ▶ **JUDr Radek Policar**, Deputy Minister for Legislation and Legal Affairs, Czech Republic
- ▶ **Ms Gabriella Battaini-Dragoni**, Council of Europe Deputy Secretary General
- ▶ **Ms Nada Al-Nashif**, UNESCO Assistant Director-General for Social and Human Sciences

10.10 Keynote speeches

- ▶ The Oviedo Convention: An achievement and a starting point
Dr Octavi Quintana (Spain), Director of the Partnership on Research and Innovation in the Mediterranean Area (PRIMA), European Commission; former Chair of the Council of Europe Steering Committee on Bioethics (CDBI)
- ▶ How to protect Human rights in the face of current biomedical developments? The significance of the Oviedo Convention
Prof. Dr. Dr. h.c. Ludger Honnefelder (Germany), Professor emeritus of Philosophy, Friedrich-Wilhelms University, Bonn; former member of the Council of Europe Steering Committee on Bioethics (CDBI)
- ▶ An ethics of integration: Novel biotechnologies and human dignity
Prof. Sheila Jasanoff (USA), Pforzheimer Professor of Science and Technology Studies, Harvard Kennedy School, Harvard University

11.30 Coffee break

12.00 Objectives of the conference

- ▶ **Prof. Dr Zvonko Magic** (Serbia), Chair of the Preparatory Group for the Conference

12.10 International case-law in bioethics: Insight and foresight

- ▶ Outcome of the high-level seminar organised on 5 December 2016 at the European Court of Human Rights
Mr Hans-Jörg Behrens (Germany), Vice-Chair of the Steering Committee for Human Rights (CDDH) of the Council of Europe

Questions/Discussion

12.40

LUNCH BREAK

14.30 SESSION II - EVOLUTION OF PRACTICES IN THE BIOMEDICAL FIELD

Rapporteurs

- ▶ **Ms Isabelle Erny** (France), Head of the Bioethics and Patients 'Rights Division of the Division of Users' Rights and Legal and Ethical Affairs at the General Secretariat of the Directorate-General for Health, Ministry of Solidarities and Health; member of the DH-BIO
- ▶ **Prof. Constantinos Phellas** (Cyprus), Vice Rector for Faculty & Research University of Nicosia, Chairman of the Cyprus National Bioethics Committee; member of the DH-BIO

14.30 **Autonomy – Consent and Privacy**

Chair: Ms Ina Verzivolli (Albania), Chair of the Ad hoc Committee for the Rights of the Child (CAHENF) of the Council of Europe

- ▶ Challenges raised by the evolution of practices for children rights
Dr Kavot Zillen (Sweden), LL.D and postdoctoral researcher, Faculty of Law, Stockholm University
- ▶ Action(s) to be undertaken at intergovernmental level to address the identified challenges
Prof. Dr Ton Liefwaard (Netherlands), Professor of Children's Rights/UNICEF Chair in Children's Rights, Law School, Leiden University

Discussion

Chair: Mr Miroslav Mikolášik, Member of the European Parliament and Chairman of the EPP Working Group on Bioethics and Human Dignity

- ▶ Challenges raised by the evolution of practices for elderly persons
Prof. Ana Sofia Carvalho (Portugal), Director of the Bioethics Institute, Universidade Católica Portuguesa (IB-UCP)
- ▶ Action(s) to be undertaken at intergovernmental level to address the identified challenges
Prof. Antonio Cherubini (Italy), Director, Geriatrics and Geriatric Emergency Care, IRCCCS- INRCA, Ancona

Discussion

16.30 Coffee break

16.45 Signing Ceremony of the Additional Protocol to the Convention on Human Rights and Biomedicine concerning genetic testing for health purposes (CETS 203) by the Czech Republic

17.15 Equity of access to health care

Chair/moderator: Ms Brigitte Konz, Chair of the Steering Committee for Human Rights (CDDH) of the Council of Europe

- ▶ Effectively exercising a right to protection of health: common or individual challenges?
Ms Marit Frogner (Norway), Member of the European Committee of Social Rights (ECSR) of the Council of Europe (Rapporteur for Article 11 of the European Social Charter)

- ▶ **Round table**
Dr Rogelio Altisent (Spain), Director of Academic Projects, Chair of Professionalism and Clinical Ethics, University of Zaragoza; **Ms Liliane Maury Pasquier** (Switzerland), Chair of the Committee on Rules of Procedure of the Parliamentary Assembly of the Council of Europe; **Ambassador Santiago Oñate Laborde** (Mexico), Permanent Observer to the Council of Europe, Mission of Mexico to the Council of Europe; **Dr Ucha Vakhania** (Georgia), Executive Director of the “Coalition Homecare in Georgia”

Discussion

18.15 End of day 1

9.00 SESSION III - NEW SCIENTIFIC AND TECHNOLOGICAL DEVELOPMENTS

Rapporteurs

- ▶ **Dr Anne Forus** (Norway), Senior Adviser, Department of Biotechnology and Health Legislation, The Norwegian Directorate of Health, member of the DH-BIO
- ▶ **Dr Tina Garani-Papadatos** (Greece), Lawyer, National School of Public Health, member of the DH-BIO
- ▶ **Prof. Stefano Semplici** (Italy), Professor of Social Ethics, Department of Literature, Philosophy and History of Art Studies, University of Rome Tor Vergata; Chair of the Bioethics Committee of the Italian Society of Pediatrics; former Chair of the International Bioethics Committee of UNESCO

9.00 Genetics – Genomics

Chair: *Prof. Milan Macek (Czech Republic), Head of Department of Biology and Medical Genetics, Charles University, Prague*

- ▶ Sequencing and analysis: Human rights challenges raised by scientific and technological developments
Prof. Anne Cambon Thomsen (France), Emeritus Research Director, Paul Sabatier University, Toulouse; member of the European Group on Ethics in Science and New Technologies, European Commission
- ▶ Principles at stake – Action(s) to be undertaken at intergovernmental level to address the identified challenges
Prof. Bartha Knoppers (Canada), Director of the Centre of Genomics and Policy, Faculty of Medicine, McGill University, Montreal

Discussion

Chair: *Dr Petra de Sutter (Belgium), member of the Council of Europe Parliamentary Assembly*

- ▶ Modification of the human genome: Human rights challenges raised by scientific and technical developments
Prof. Jonathan Montgomery (United Kingdom), Professor of Health Care Law, University College, London; former Chair of the Nuffield Council on Bioethics; member of the European Group on Ethics in Science and New Technologies, European Commission
- ▶ Principles at stake – Action(s) to be undertaken at intergovernmental level to address the identified challenges
Prof. Ewa Bartnik (Poland), Professor of Genetics, Faculty of Biology, University of Warsaw; member of the International Bioethics Committee of UNESCO

Discussion

10.40 Coffee break

11.10 Brain technologies

Chair: Mr Jean-Yves Le Déaut (France), former member of the Council of Europe Parliamentary Assembly

- ▶ Human rights challenges raised by scientific and technical developments
Prof. Nikola Biller-Andorno (Switzerland), Director of the Institute of Biomedical Ethics and history of medicine, Center for Medical Humanities, University of Zürich
- ▶ Principles at stake – Action(s) to be undertaken at intergovernmental level to address the identified challenges
Prof. David Winickoff (OECD), Senior Policy Analyst, Secretary of the Working Party on Bio-, Nano- and Converging Technologies (BNCT)

Discussion

12.00 Information technologies/NBIC and Big data

Chair: Mrs Tesi Aschan (Sweden), Vice-Chair of the Committee on Bioethics (DH-BIO) of the Council of Europe

- ▶ Human rights challenges raised by scientific and technical developments
Ms Antoinette Rouvroy (Belgium), The Research Centre in Information, Law and Society (CRIDS), Namur University; **member of the Ethics Advisory Group of European Data Protection Supervisor**
- ▶ Principles at stake – Action(s) to be undertaken at intergovernmental level to address the identified challenges
Ms Alessandra Pierucci (Italy), Chair of the Council of Europe Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD)

Discussion

13.00 LUNCH BREAK

15.00 SESSION IV – PAVING THE WAY FOR A STRATEGIC ACTION PLAN

15.00 Priority issues and action proposals

Moderator: Prof. Dr. med. Christiane Woopen (Germany), Professor of Ethics and Theory of Medicine, University of Cologne; member of the International Bioethics Committee of UNESCO; Chairperson of the European Group on Ethics in Science and New Technologies, European Commission

- ▶ **Round table**
Prof. Nikola Biller-Andorno (Switzerland), on behalf of WHO, Director of the Institute of Biomedical Ethics and History of Medicine, WHO Collaborating Center in Bioethics, University of Zurich; **Prof. Jean-François Delfraissy** (France), President of the National Ethics Committee; **Dr Lyalya**

Gabbasova (Russian Federation), Adviser to the Health Minister; **Ms Paula Kokkonen** (Finland), former emeritus Chair person of the National Advisory Board on Health Care Ethics, former Chair of the Council of Europe Steering Committee on Bioethics (CDBI); **Ms Brigitte Konz** (Luxembourg), Chair of the Steering Committee for Human Rights (CDDH) of the Council of Europe; **Dr Petra de Sutter** (Belgium), member of the Council of Europe Parliamentary Assembly

16.30 CONCLUSIONS OF THE GENERAL RAPPOREUR

- ▶ **Dr Siobhan O’Sullivan** (Ireland), Lecturer in Healthcare Ethics and Law, Royal College of Surgeons; Vice Chair of the European Group on Ethics in Science and New Technologies, European Commission

17.00 SESSION V – CLOSING

- ▶ **Dr Beatrice Ioan** (Romania), Chair of the Committee on Bioethics (DH-BIO) of the Council of Europe