COUNCIL OF EUROPE

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Strasbourg, 15 June 2017 **DH-BIO/abr RAP 11**

COMMITTEE ON BIOETHICS

(DH-BIO)

11th MEETING
Strasbourg, 6-8 June 2017

ABRIDGED REPORT

I. Adoption of the agenda

1. The Committee on Bioethics (DH-BIO) held its 11th meeting in Strasbourg from 6 to 8 June 2017. The agenda of the meeting and the list of participants appear in Appendix I and Appendix II to this abridged report.

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

2. The DH-BIO was informed that on 11 May 2017, Portugal had ratified two Additional Protocols to the Convention on Human Rights and Biomedicine, namely the one concerning Transplantation of Organs and Tissues of Human Origin (CETS no. 186), as well as the one concerning Biomedical Research (CETS no. 195). The Protocols would enter into force in respect of Portugal on 1 September 2017.

III. Developments in the field of bioethics

3. The DH-BIO took note of the developments in the field of bioethics within the member states, as well as in international organisations. It was also informed 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

4. The DH-BIO examined the draft Additional Protocol as revised by the Drafting Group at its meeting on 26-27 January 2017 in the light of the comments received during the public consultation and sent by delegations.

5. Representatives of the following disability rights INGOs had been invited to participate in this session of the meeting: European Disability Forum (EDF), Rehabilitation International (RI) and European Association of Service Providers for Persons with Disabilities (EASPD).

6. A number of changes were introduced to the draft Protocol. The Secretariat would send out the draft as revised to delegations.

7. The DH-BIO thanked the Drafting Group for its work and agreed that further elaboration of the draft Protocol should continue between plenary meetings at the level of delegations, in the form of consultation meetings.

8. **Delegations were invited to send written comments on the draft Protocol as well as the draft explanatory report, together with drafting proposals, by 10 July 2017**.

V. Cooperation activities

9. The DH-BIO took note of the request made by the Cypriot authorities for a seminar on end-of-life issues to be organised in Cyprus in spring 2018.

10. The DH-BIO was informed that two seminars would be organised in Moscow on 29-30 June 2017, in cooperation with the Russian Ministry of Health and Academy of Justice. The first seminar would focus on the principle of free and informed consent, and the second would aim at introducing and discussing the project of a course on essential principles of bioethics – an online course to be developed for legal and health professionals following the methodology of the HELP programme.

11. The Secretariat also underlined that bioethics was part of the priorities of the Council of Europe Action Plan for Belarus 2016-2017 and that specific activities in Belarus were foreseen under this framework.

VI. Emerging Technologies

12. The DH-BIO agreed to elaborate a practical guide for the development of democratic discourse and critical engagement along the lines proposed by its Bureau.

13. Delegations were called to express interest to participate in the work of an ad-hoc group entrusted with the elaboration of the guide. The DH-BIO took note in this context of the interest expressed by Ms Anne Forus (Norway) and Ms Anneli Torronen (Finland) as well as Mr Peter Mills (former UK representative) to participate in this work for which Ms Tesi Aschan (Sweden) will act as rapporteur.

14. The exact calendar of the work will be discussed with the rapporteur and members of the ad hoc group in coordination with the Bureau.

VII. Prohibition of financial gain

15. The DH-BIO discussed the draft guide as revised by the Bureau in the light of the comments made by delegations. It focused in particular on the introductory paragraphs as well as on paragraph 23 on fixed-rate compensation schemes.

16. The DH-BIO agreed on the content of the guide as discussed during the meeting.

17. The Bureau was entrusted with the task of carrying out an editorial toilette of the guide with a view to its adoption at the 12th plenary meeting. As agreed at the last plenary meeting, the CD-P-TO and the CD-P-TS will also be invited to adopt the text.

VIII. Study on children's rights

18. The DH-BIO took note of the draft study "From laws of Practice: towards a roadmap to strengthen children's rights in the Era of Biomedicine", prepared by Prof. Ton Liefaard, Prof. Aart Hendricks and Dr Daniella Zlotnik from the University of Leiden (NL). It expressed its appreciation of the work achieved. It subsequently held an exchange of views on topics raised in the study with two of the authors.

19. **Delegations were invited to send possible complementary comments on the draft study by Thursday 15 June 2017 with a view of its finalisation.**

IX. International conference on the occasion of the 20th anniversary of the Oviedo Convention

20. The DH-BIO congratulated the Preparatory Group for the draft program of the Conference marking the 20th anniversary of the Oviedo Convention (Strasbourg, 24-25 October 2017) prepared in cooperation with the Bureau and the Secretariat.

21. Invitation message together with the draft program will be sent to Delegations to forward it to interested persons.

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

22. The DH-BIO agreed to appoint rapporteurs for each specific topic to facilitate co-ordination and progress in the related work during and between plenary meetings.

23. Delegations were invited to liaise with their counterparts in CDDH, as well as to visit regularly the Permanent Representation of their country regularly to update them on the work of the Committee. The Secretariat would provide a list of contact details.

XI. Relations with other international bodies

24. The DH-BIO took note of the document prepared by the Secretariat with the list of meetings with other international organisations.

XII. Date of next meetings

25. The DH-BIO agreed on the following dates for its next meetings:

- 12th meeting of the DH-BIO: 24-27 October 2017 in Strasbourg (24-25 October: International conference on the occasion of the 20th anniversary of the Oviedo Convention)
- 13th meeting of the DH-BIO: 29 May-1 June 2018 (to be organised in Cyprus at the invitation of the national authorities subject to budgetary resources)

XIII. Cooperation with other Committees

26. Members of the DH-BIO were invited to express by 10 July 2017 their interest in assisting the Ad hoc Committee for the Rights of the Child, in taking due account of relevant ethical issues in the development of standards on age assessment, to ensure that special measures and safeguards are in place to protect unaccompanied and other children affected by the migrant and refugee crisis.

27. The DH-BIO was informed that it would be invited to send comments on the revised version of the draft Recommendation on health-related data that will be resulting from the discussion at the next meeting of the Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD) to be held on 19-21 June 2017.

XIV. Other business

PACE Rec20102(2017) on Technological convergence, artificial intelligence and human rights

28. The DH-BIO adopted its comments on PACE Recommendation 2102 (2017) – “Technological convergence, artificial intelligence and human rights” to be forwarded to the Committee of Ministers in reply to its request.

Intersex children

29. The DH-BIO agreed to include the topic of Intersex Children in its program of activities.

30. **Members of the DH-BIO were invited to express interest to act as Rapporteur on this topic by 10 July 2017.**

Genetics and genomics

31. Following the information provided by the representative of the PACE on the current work on the use of new genetic technologies in human beings, and recalling its statement on Genome Editing Technologies (adopted on 2 December 2015), the DH-BIO agreed to designate a rapporteur for its future work on genetics and genomics, including genome editing. Dr Ingo Härtel (Germany) was entrusted with this responsibility.

Gender equality

32. Prof. Constantinos Phellas (Cyprus) briefly referred to his tasks as the newly designated rapporteur on gender equality. He informed about his intention to contact delegations in view of more specific initiatives which could be considered to address gender equality issues relevant to the work of the DH-BIO.

APPENDIX I
Agenda of the 11th meeting of the DH-BIO

LIST OF ITEMS

1. Adoption of the draft agenda


2. 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


3. Developments in the field of bioethics

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


5. Cooperation activities

6. Emerging technologies

7. Prohibition of financial gain

8. Study on children's rights

9. International Conference marking the 20th anniversary of the Oviedo Convention

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


11. Relations with other international bodies

12. Dates of the next meetings


13. Cooperation with other committees

14. Other business

15. Decisions taken by the DH-BIO at its 11th meeting

TUESDAY 6 JUNE MORNING (9.30 – 13.00)	
09.30	**1. Adoption of the draft Agenda**
	2. 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
	3. Developments in the field of bioethics Delegations, including observers, are invited to send information in writing. a. Developments in member states and other states b. Developments in the field of bioethics in international organisations c. Developments in other Council of Europe bodies d. Developments at the European Court of Human Rights
	11. Relations with other international bodies
	5. Cooperation activities *- Seminar on free and informed consent to be held in Moscow, June 2017* *- Cooperation activities within the framework of the Council of Europe Action plan for Belarus 2016-2017*
11.00	**7. Prohibition of financial gain** - Presentation of the draft Guide revised by the Bureau in the light of the comments made by delegations - Discussion on the revised document with a view to agreeing on its content and; following its editorial toilette, its adoption at the 12th plenary meeting.
	TUESDAY 6 JUNE AFTERNOON (14.30 – 18.00)
14.30	**(to continue where necessary) 7. Prohibition of financial gain**
	10. Working methods and future activities of the DH-BIO a) Working methods b) Programme of activities for the 2018-2019 biennium
	13. Cooperation with other committees 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)* - Exchange of information on activities of common relevance
	14. Other business **a. Rec 2102(2017) of the PACE – Technological convergence, artificial intelligence and human rights** - Examination of the draft comment prepared by the Secretariat in the light of the remarks received from delegations with a view to its adoption **b. Intersex children** Discussion with a view to a decision on the inclusion of this topic in the work programme of the DH-BIO **c. HELP and Bioethics draft course** **d. Gender equality** Exchange on ways to strengthen the gender perspective in the work of the DH-BIO
WEDNESDAY 7 JUNE MORNING (9.00 – 13.00)	
	4. 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 draft Additional Protocol revised by the Drafting Group in the light of the comments made during the public consultation and by delegations - Exchange of views on the further organisation of the drafting process with a view to a decision
WEDNESDAY 7 JUNE AFTERNOON (14.30 – 18.00)	
14.30	**(to continue where necessary) 4. Additional Protocol on the protection of the human rights and dignity of persons with mental disorders with regard to involuntary placement and involuntary treatment**
	6. Emerging technologies - Discussion on the objective(s) of the work with a view to a decision on its specific objective and its practical organisation.
	9. International Conference marking the 20th anniversary of the Oviedo Convention
	- Presentation of the draft programme - Where appropriate, discussion on the draft programme with a view to its finalisation

THURSDAY 8 JUNE MORNING (9.00-13.00)	
	8. Study on children's rights - Presentation of the study analysing existing international legal provisions relevant to children rights in the light of developments in the biomedical field (Prof. Ton Liefaard, UNICEF Professor of Children's Rights, and Prof. Aart Hendricks, Leiden University, the Netherlands) - Exchange of views with DH-BIO delegations on the study
	12. Dates of the next meetings Dates proposed: - 12th meeting of the DH-BIO: 24 – 27 October 2017 (International Conference marking the 20th anniversary of the Oviedo Convention on 24-25 October) - Proposed: 13th meeting of the DH-BIO: 29 May to 1 June 2018 (alternative 22-25 May 2018)
	15. Decisions taken by the DH-BIO at its 11th meeting - Approval of the list of decisions

APPENDIX II
List of participants

MEMBER STATES / ETATS MEMBRES

Albania/Albanie - **apologised/excusé**

Andorra/Andorre – Mme Imma RODRIGUEZ, Carrer Pau Casals 2, 3r 1a. AD 500-ANDORRA LA VELLA

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

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, boite 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 Sørensen **apologised/excusée**

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

Finland/Finlande – 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

Anneli TORRONEN, Ministerial Adviser, MD, Ph.D., Ministry of Social Affairs and Health, P.O.Box 33 FIN-00023 GOVERNMENT

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

France – 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

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 **apologised/excusée**

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 – Volker SCHÖFISCH, Federal Ministry of Justice and Consumer Protection, Division III B 6, Mohrenstraße 37, D-10117 Berlin **apologised/excusé**

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

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 & Pateints' Rgihts, 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 **apologised/excusé**

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

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

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 Legala, 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. 36ª, CARANSEBES, jud. CARAS-SEVERIN 325400

Russia/Russie – Mr Boris YUDIN, Director, Institute of Human Studies, Russian Academy of Sciences, Volkhonka 14, MOSCOW 119992 **apologised/excusé**

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 **apologised/excusé**

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 – Mª 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 **apologised/excusé**

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

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

Ton LIEFAARD, UNICEF Professor of Children's Rights, Leiden University, Law School, Kamerlingh Onnes Building, Steenschuur 25, Room B 3.33, P.O. Box 9520, 2300 RA Leiden, The Netherlands

Daniella ZLOTNIK, Leiden University, Law School, Kamerlingh Onnes Building, Steenschuur 25, Room B 3.33, P.O. Box 9520, 2300 RA Leiden, The Netherlands

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

CDDH – Mr Alfonso de SALAS, Secretary of the CDDH **apologised/excusé**

Mme Brigitte KONZ, Juge de Paix directrice, Cité judiciaire, Plateau du St Esprit, Bâtiment JP - L-1475 Luxembourg **apologised/excusée**

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/excusée**

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

CAHDPH - Ms. Ita MIRIANASHVILI, Head of Section, Rights of persons with disabilities **apologised/excusée**

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 Aysegul ELVERIS, Administrator

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/excusé**

CONFERENCE OF INGOS/ CONFÉRENCE DES OING - Mr Michel AGUILAR, Chair of the Human Rights Committee of the Conference of INGOs / Président de la Commission Droits de l'homme de la Conférence des OING

Mr Thierry MATHIEU, Vice-Chair of the Democracy, Social Cohesion and Global Challenges Committee of the Conference of INGOs, Member of the International Association for Research in Hospital Hygiene / Vice-Président de la Commission démocratie, cohésion sociale et enjeux mondiaux de la Conférence des OING et membre de l'Association Internationale pour la Recherche en Hygiène Hospitalière (AIRHH) **apologised/excusé**

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 **apologised/excusé**

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 Comission of Bioethics. Calz. Arenal No. 134, Col. Arenal-Tepepan, Deleg. Tlalpan, Mexico D. F.

USA/Etats-Unis d'Amérique – **apologised/excusé**

Belarus - Denis EFIMOV, surgeon of the Republican Scientific and Practical, Center for Transplantation of Organs and Tissues, 9th Minsk City Clinical

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

UNESCO – Orio IKEBE, Programme Specialist, Bioethics and Ethics of Science Section, Social and Human Sciences Sector, 7, Place de Fontenoy 75352 Paris 07 SP France

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 **apologised/excusée**

April Philippa TASH, Programme Specialist, Bioethics and Ethics of Science and Technology Section, Social and Human Sciences Sectore, United Nations Educational Scientific and Cultural Organization (UNESCO), 7 place de Fontenoy (office 3.118), F-75352 Paris 07 France SP **apologised/excusée**

OECD/OCDE – Mr David WINICKOFF, STI/STP **apologised/excusé**

World Health Organisation/Organisation Mondiale de la Santé (WHO/OMS) – Dr Abha SAXENA (MD), Coordinator, Global Health Ethics, Secretary, Research Ethics Review Committee (ERC), HIS/KER, Cluster of Health Systems and Innovation, World Health Organization, 20, Avenue Appia, CH- 1211, Geneva 27, Switzerland **apologised/excusée**

Dr Andreas REIS, Technical Officer, HIS/KER, Cluster of Health Systems and Innovation, World Health Organization, 20, Avenue Appia, CH- 1211, Geneva 27, Switzerland **apologised/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

NGO

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

Ms Gemma HOPE, Head of Policy & Research, Shaw Trust

European Disability Forum (EDF) - Mr John Patrick CLARKE, Vice-President of European Disability Forum

Ms Alva FINN, Human Rights and Policy office, Mental Health Europe

Ms Jolijn SANTEGOEDS, Board member of the European Network of (ex-) Users and Survivors of Psychiatry (ENUSP)

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. Kristina FELT, Trainee / Stagiaire

INTERPRETERS / INTERPRETES

Sarah ADLINGTON
Amanda BEDDOWS
Shéhérazade HOYER
Christine TRAPP