

CONSEIL DE LEUROPE

DH-BIO/abr RAP16

Strasbourg, 29 November 2019

# COMMITTEE ON BIOETHICS (DH-BIO)

# 16<sup>th</sup> meeting

19-21 November 2019

Strasbourg

Abridged Report

# I. Adoption of the agenda

- 1. The Committee on Bioethics (DH-BIO) held its 16<sup>th</sup> meeting in Strasbourg from 19-21 November 2019. The list of participants and the agenda of the meeting appear in Appendices I and II to this report.
- 2. The Chair, Tesi Aschan (Sweden), welcomed the new members of the DH-BIO.

# II. <u>Developments in the field of bioethics</u>

- 3. The Committee took note of the developments in the field of bioethics within the member states, including with a view to a ratification of the Oviedo Convention. It was also informed of the relevant developments in other Council of Europe bodies and in the relevant case-law of the European Court of Human Rights.
- 4. The Committee was also informed about relevant developments in international organisations, namely in relation to activities relevant to genome editing technologies and artificial intelligence.

#### III. 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 (to be dealt with in writing)

5. The Committee took note of the information sent in written form on the current process towards signature and/or ratification of the Convention on Human Rights and Biomedicine (Oviedo Convention) and/or its Additional Protocols in some member and observer states.

# IV. Strategic Action Plan

- 6. The Chair of the drafting group, Dr Siobhan O'Sullivan (Ireland), introduced the revised draft Strategic Action Plan. She thanked DH-BIO members for having provided their written comments on the previous draft and for indicating their preferences among the proposed actions based on 'SMART' criteria. She underlined the importance of undertaking a manageable number of actions which are both realistic and achievable having regard to the timing of their realisation.
- 7. The Committee welcomed the revised draft Strategic Action Plan and thanked the drafting group for its efforts. Following a series of presentations by and exchanges with the chair and members of the drafting group regarding the different pillars and related actions, the Committee adopted the Strategic Action Plan in its current form by unanimity of the votes cast with one abstention. It agreed on a certain number of editorial changes that were mentioned during the discussions.
- 8. The Bureau, in coordination with the Chair of the Drafting Group and the Secretariat, was entrusted with the task of proposing methodologies for the actions included in the Strategic Action Plan to be presented to the DH-BIO at the next plenary meeting.
- 9. The Committee agreed to organise a conference for the launching of the Strategic Action Plan to be held on 2 June 2020, first day of the 17<sup>th</sup> plenary meeting. It entrusted the Bureau with the task of organising this event.

# V. <u>Additional Protocol on the protection of the human rights and dignity of persons</u> with mental disorders with regard to involuntary placement and involuntary treatment

10. The Committee expressed its general support for the work initiated during the consultation meeting on 14 October 2019 to continue through consultation of delegations with a view to present a revised draft at the next plenary meeting. The Committee entrusted the Bureau with organising the further drafting process and designated Ms Sarah Rueda (France) as rapporteur for this work.

# 11. Delegations were invited to submit written comments on the revised text (DH-BIO (2019)20) together with their drafting proposals, <u>by 25 January 2020</u>.

# VI. <u>Comments on PACE Rec 2158(2019) – "Ending coercion in mental health: the need</u> <u>for a human-rights based approach"</u>

12. The Committee, by unanimity of votes cast with two abstentions, adopted its comments on PACE Rec 2158(2019) – "Ending coercion in mental health: the need for a human-rights based approach" to be submitted to the Committee of Ministers.

# VII. Study on good practices in mental healthcare - How to promote voluntary measures

13. The Committee was informed about the agenda of a stakeholder consultation meeting aimed at refining the scope of the study which would take place in Brussels on 26 November 2019.

# VIII. <u>Question to the European Court of Human Rights under Article 29 of the Oviedo</u> <u>Convention</u>

14. The Representatives of the Parties to the Oviedo Convention, by unanimity of votes cast with two abstentions, decided to submit a request for an advisory opinion to the European Court on Human Rights under Article 29 of the Oviedo Convention. They agreed on two questions relating to the interpretation of Articles 7 and 26 of the Oviedo Convention proposed by the Bureau.

# IX. Public debate

- 15. The Chair presented the revised draft guide to public debate with particular regard to the changes made to it since the last plenary meeting: notably the restructuring of its earlier sections, a revised definition of "public debate" in line with Article 28 of the Oviedo Convention, better differentiation between the terms "public engagement" and "public debate" to facilitate translation into French and possibly other languages, and the elaboration and referencing of country examples of public debate.
- 16. The Committee welcomed the guide which it considered to be a useful tool and a valuable source of reference. It congratulated the members of the drafting group for their efforts in rendering the document both clear and well-structured.
- 17. The Committee unanimously adopted the guide in its current form subject to certain editorial changes and the insertion of additional references to examples of public debate in the Russian Federation and in Belarus.
- 18. The need for better geographical balance in the selected resources section of the guide was discussed. To that end, the delegations were invited to send to the Secretariat, at the latest by 10 December 2019, any proposals for additional resources.

19. The Chair presented a pilot online version of the guide to promote its accessibility and general use. The Committee welcomed the initiative. Several members of the Committee also expressed their interest and willingness to translate the guide into their national languages.

# X. Gender equality

- 20. The Committee was informed that the gender rapporteur, Prof. Constantinos Phellas, had stepped down from the Committee due to other work commitments. In order to designate a new rapporteur, the chair invited expressions of interest from Committee members.
- 21. The Committee received the candidature of Prof. Iuliia Davydova (Ukraine) and subsequently agreed to designate her as gender equality rapporteur.

### XI. Cooperation with other committees

- 22. The Chair of the Ad-Hoc Committee on the Rights of the Child (CAHENF), Ms Maria-Andriani Kostopoulou, informed the DH-BIO on the Committee's ongoing and future work. This is followed by an exchange of views on further co-operation within the framework of the Strategic Action plan.
- 23. The Chair of the CAHENF specified that clear reference was made in the terms of reference of the future Steering Committee on the Rights of the Child (CDENF), to close cooperation with DH-BIO on developing a non-legally binding instrument on child participation in decision making in biomedicine. She also referred to the continuing work on age determination for the purpose of which the DH-BIO members have already provide some expertise.

#### XII. Cooperation activities

24. The Committee was informed of the planned cooperation activities, particularly as part of the Action Plan for Armenia.

### XIII. Bureau election

- 25. The Committee re-elected by acclamation Ms Tesi Aschan (Sweden) as Chair for a oneyear term.
- 26. The Committee re-elected by acclamation Dr Ritva Halila (Finland) as Vice-Chair for a one-year term.
- 27. The Committee elected by acclamation Mr Tomáš Doležal (Czech Republic) as member of the Bureau for a term of two years, renewable once.

#### XIV. Presentation of the studies on genome editing and exchange with delegations

- 28. Following presentations on developments in genome editing technologies and the ethical issues they raise, by Prof. Heidi Howard (Uppsala University, Sweden, by video presentation) and by Prof. Ian Toma (George Washington University, USA), and an overview on current initiatives at international level, the Committee held an exchange of view on the questions raised.
- 29. It was agreed to invite Prof. Heidi Howard for an exchange of views with the delegations at the next plenary meeting. In the meantime, delegations were invited to

communicate the information provided by the two experts at governmental level with a view to provide the perspectives of their authorities in the discussion process that will continue at the next plenary meeting and which aims at assessing whether the provisions of the Oviedo Convention are appropriate to address the ethical and legal challenges raised by technological developments in genome editing.

# XV. Dates of the next meetings

- 30. The DH-BIO agreed on the following dates for its next meetings to be held in Strasbourg:
  - 17th meeting of the DH-BIO: 2-5 June 2020
  - 18th meeting of the DH-BIO: 3-6 November 2020

### XIV. Decisions

31. The Committee adopted the list of decisions taken during the meeting.

### XV. Other business

Impact of Rec(2016)8 on the processing of health-related data for insurance purposes, including data resulting from genetic testing

- 32. The Committee took note of the compilation of replies to the questionnaire on the impact of Rec (2016)8 and invited Delegations not having done so far to send their replies and for the other, where appropriate, to complement the available information.
- 33. Following a Bureau proposal to develop tools to visualize the information submitted in a dynamic way, the DH-BIO entrusted the Secretariat with exploring the technical feasibility of such proposal.

#### Appendix I List of participants

#### MEMBER STATES / ETATS MEMBRES

#### Albania/Albanie -

Andorra/Andorre - Mme Imma RODRIGUEZ, Batllia d'Andorra

<u>Armenia/Arménie</u> - Ms Lusine KOCHARYAN, Head of Medical Care Policy Department, Ministry of Health of the Republic of Armenia apologised/excusée

<u>Austria/Autriche</u> - Mag. Martina ERLEBACH, juge, référendaire de la section civile, droit national de la famille

Dr Isabelle HASSLER, Federal Chancellery of Austria / Co-ordination Science, Research, Technology, Education, Social issues, Health, Secretariat of the Austrian Bioethics Commission

apologised/excusée

Dr Renate FALLY-KAUSEK, Medical Officer, Federal Ministry of Health apologised/excusée

<u>Azerbaijan/Azerbaïdjan</u> - 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

<u>Belgium/Belgique</u> - Mr Paul COSYNS, Universiteit Antwerpen, Dienst Psychiatrie van UZA, Emeritus Professor

Bosnia and Herzegovina/Bosnie-Herzégovine - Mr Dalibor PEJOVIC, Head of Unit for Statistics and Analytical Affairs and Reporting in Health, Department for Health apologised/excusé

Ms Dunja ŠMITRAN, Ministry of Civil Affairs of Bosnia and Herzegovina apologised/excusée

<u>Bulgaria/Bulgarie</u> - Ms Sylvia TOMOVA, Ministry of Health, Legal Directorate, Chief Legal Advisor apologised/excusée

<u>Croatia/Croatie</u> - Dr. Vanja NIKOLAC, Head of Service, Service for blood, tissues and cells inspection, Ministry of Health **apologised/excusée** 

<u>Cyprus/Chypre</u> - Prof. Constantinos N. PHELLAS, Chair of the Cyprus National Bioethics Committee, University of Nicosia **apologised/excusé** 

<u>Czech Republic/République Tchèque</u> - (Ms) doc. PhDr. Ing. Hana KONEČNÁ, Ph.D., Jihočeská univerzita v Českých Budějovicích, Zdravotně sociální fakulta, Katedra klinických a preklinických oborů

Doc. JUDr. Tomáš DOLEŽAL, Ph.D., LL.M., Head of the Department of Private Law and Head of the Research Unit for Medical Law and Bioethics, Czech Academy of Science, Institute of State and Law

Denmark/Danemark - Ms Anne-Sofie DUELUND LASSESEN, Legal officer, Ministry of Health

Ms Sabine GODSVIG LAURSEN, Ministry of Health

Estonia/Estonie - Dr Aime KEIS, Assistant, Chief lecturer of medical ethics, Faculty of Medicine, University of Tartu

**<u>Finland/Finlande</u>** - Ms Katja FOKIN, Legal Officer, Unit for Human Rights Courts and Conventions, Legal Service, Ministry of Foreign Affairs

apologised/excusé

# apologised/excusée

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

**<u>France</u>** - Mme Anne FREUDENREICH, Sous-direction des droits de l'Homme, Direction des affaires juridiques, Ministère de l'Europe et des affaires étrangères

Mme Sarah RUEDA, Division droits des usagers, affaires juridiques et éthiques, Direction générale de la santé, Ministère des solidarités et de la santé

Mme Maïalen MALLET, Division droits des usagers, affaires juridiques et éthiques, Direction générale de la santé, Ministère des solidarités et de la santé

Mme Guilaine GANRY, Bureau du droit des personnes et de la famille, Direction des affaires civiles et du sceau, Ministère de la Justice

Dr Jacques MONTAGUT, Directeur de l'IFREARES

<u>Georgia/Géorgie</u> - Dr Givi JAVASHVILI, Head of Family Medicine Department, State Medical Academy of Georgia, Chairman of the National Council on Bioethics

<u>Germany/Allemagne</u> - Dr Nils GODENDORFF, Legal Officer, Bundesministerium der Justiz und für Verbraucherschutz, Unit III B 6, Division for Insurance Law; IOPC; Genetic Diagnotics; UNCITRAL

Dr. Ingo HÄRTEL, Federal Ministry of Health, Division 317

Prof. Dr. Elmar DOPPELFELD (Honorary chair of the "Permanent Working Party of Research Ethics Committees in Germany Inc.")

Prof. Dr. Dr. Thomas HEINEMANN, Philosophical-Theological University of Vallendar (PTHV)

Dr. Stefan OSSEGE, Federal Ministry of Education and Research, Division 612

Greece/Grèce - Dr Stamatia GARANIS-PAPADATOS, Lecturer, National School of Public Health

Hungary/Hongrie - Prof. Ernö BÁCSY, MD, PhD, DSc, Medical Research Council of Hungary

Iceland/Islande - Mr Rögnvaldur G. GUNNARSSON, Legal Advisor, Ministry of Welfare

apologised/excusé

Ms. Thorunn STEINSDOTTIR, Legal Advisor, Ministry of Welfare apologised/excusée

Ireland/Irlande - Dr Siobhan O'SULLIVAN, Chief Bioethics Officer, An Roinn Sláinte Department of Health, Teach Hawkins

<u>Italy/Italie</u> - Prof. Assunta MORRESI, Prof. Associato di Chimica Fisica, Dipartimento di Chimica, Biologia e Biotecnologie, Università degli Studi di Perugia

<u>Latvia/Lettonie</u> - Dr.Vents SĪLIS, Assistant Professor at Riga Stradins University, Department of Humanities

Liechtenstein -

Lithuania/Lituanie - Ms Asta ČEKANAUSKAITĖ, Chief Specialist and Acting Director of Lithuanian Bioethics Committee

Luxembourg - Ms Delphine STOFFEL, Ministère de la Santé, Division des Affaires Juridiques

<u>Malta/Malte</u> - 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

**<u>Republic of Moldova/République de Moldova</u>** - Ms Rodica GRAMMA, Associate Professor, State University of Medicine and Pharmacy (USMF)

<u>Monaco</u> - M. Xavier RAUSCHER, Administrateur Juridique au Service du droit International, des droits de l'homme et des libertés fondamentales

<u>Montenegro/Monténégro</u> - Ms Olivera MILJANOVIC, Prim. doc., Director of the Centre for Medical Genetics and Immunology, Medical Centre of Montenegro

Netherlands/Pays-Bas - Ms Sanne VAN WEEZEL, Ministry of Health, Welfare and Sports

Mr Harrie STORMS, Ministry of Health, Welfare and Sports

<u>North Macedonia/Macédoine du Nord</u> - Ms Olgica VASILEVSKA, Senior Counselor, Directorate for Multilateral Relations and Security Cooperation, Sector for Council of Europe, OSCE and other European Organizations, Ministry of Foreign Affairs

<u>Norway/Norvège</u> - Mrs Anne FORUS, Senior Adviser, ph.d, Biotechnology and health legislation department, Division of specialised health care services, Norwegian Directorate of Health

Ms Vårin HELLEVIK, Norwegian Directorate of Health, Department of Specialized Mental health care and Addiction Treatment

Ms Camilla Closs WALMANN, Senior Adviser, Department for Biotechnology and Health Law, Norwegian Directorate of Health apologised/excusée

Poland/Pologne - Ms Mariola GROCHULSKA, Département des droits de l'homme, Ministère de la Justice

Portugal - Prof. Jorge SOARES, Président du Conseil National d'Ethique pour les Sciences de la Vie

**<u>Romania/Roumanie</u>** - Mrs Beatrice Gabriela IOAN, Associate Professor, President of the Bioethics Commission of the Romanian College of Physicians, Institutul de Medicina Legala

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

Russian Federation/Fédération de Russie - Ms Lyalya GABBASOVA, Dr.MS, Assistant to the Minister, Ministry of Health of the Russian Federation apologised/excusée

Ms Maria ORESHINA, 1st secretary of the Department of European cooperation, Ministry of Foreign Affairs

Ms Daria KHUKHREVA, Ministry of Health of the Russian Federation

Ms Olga OPANASENKO, Counsellor of the Department of the Humanitarian Cooperation and Human Rights of the Ministry of Foreign Affairs of the Russian Federation

San Marino/Saint-Marin - Dr Luisa BORGIA, Vice-President of the National Ethics Committee

<u>Serbia/Serbie</u> - 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

<u>Slovakia/Slovaquie</u> - Prof. Jozef GLASA, MD, PhD, PhD; Institute of Pharmacology and Clinical Pharmacology, Institute of Health Care Ethics, Slovak Medical University in Bratislava; Institute of Medical Ethics and Bioethics n.f.; Ethics Committee (NEC), Ministry of Health SR

Slovenia/Slovénie - Prof. Marjeta TERČELJ ZORMAN, Dr.Med.

<u>Spain/Espagne</u> - M<sup>a</sup> Concepción MARTIN ARRIBAS, Subdirección General de Investigación en Terapia Celular y Medicina Regenerativa – Instituto de Salud Carlos III – ISCIII

Prof. Carlos M. ROMEO – CASABONA, Professor of Penal Law, Head, Inter-University Chair in Law and the Human Genome

Mme Leonor RUIZ SICILIA, Coordinatrice de la Stratégie de Bioéthique du Système de Santé Publique, Andalousie, Département Ministériel de la Santé et de la Famille - Membre du Comité de Bioéthique de l'Espagne **apologised/excusée** 

<u>Sweden/Suède</u> - Mrs Tesi ASCHAN, Legal Adviser, The National Board of Health and Welfare, Socialstyrelsen

Ms Kerstin CARLSSON, political scientist and international relations officer, National Board of Health and Welfare, Socialstyrelsen

<u>Switzerland/Suisse</u> - Dr Martin GÖTZ, Office fédérale de la santé publique, Division Biomédecine, collaborateur scientifique

Ms Nina SCHERRER, Wissenschaftliche Mitarbeiterin, Sektion Forschung am Menschen, Eidgenössisches Departement des Innern EDI, Bundesamt für Gesundheit BAG, DB Öffentliche Gesundheit, Abteilung Biomedizin apologised/excusée

<u>Turkey/Turquie</u> - Prof. Ergun ÖZSUNAY, Professor of Civil, Comparative Law and EU Private law, Istanbul Culture University, Faculty of Law

<u>Ukraine</u> - Ms Iuliia DAVYDOVA, Professor, Head of High-Risk Pregnancy Department, Institute of Pediatrics, Obstetrics and Gynecology, member of Local Bioethics Committee

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 **apologised/excusée** 

<u>United Kingdom/Royaume-Uni</u> - Dr Mark BALE, Deputy Director, Health Science & Bioethics Division, Department of Health

#### **INVITED GUESTS**

Mme Isabelle ERNY, ancienne Attachée principale d'administration centrale, Ministère de la Santé, Direction Générale de la Santé, Secrétariat Général, Division droit, éthique et appui juridique, France

Prof. Stefano SEMPLICI, Professor of Moral Philosophy, Tor Vergata University, Italia

Dr Kristof VAN ASSCHE, Postdoctoral researcher, Bioethics Institute Ghent, Ghent University, Belgium

Ms Heidi HOWARD, PhD Senior Researcher, Centre for Research Ethics & Bioethics, Uppsala University, Sweden apologised/excuse

Mr Peter MILLS, Assistant Director Nuffield Council on Bioethics, United Kingdom

Professor Ian TOMA, George Washington University, United States

PARTICIPANTS

CDCJ -

CDDH - Mme Brigitte KONZ, Juge de Paix directrice, Cité judiciaire, Luxembourg

CD-P-TO - Ms Marta LOPEZ FRAGA, Secretary of the CD-P-TO	apologised/excusée
T-PD - Ms Sophie KWASNY, Administrator	apologised/excusée
Mr Peter KIMPIAN, Administrator	apologised/excusé

CPT - Mr Michael NEURAUTER, Head of Division of the Secretariat of CPT

**CAHENF** - Ms Maria-Andriani KOSTOPOULOU, Chair of the Ad Hoc Committee for the Rights of the Child (CAHENF)

Ms Livia STOICA, Administrator

HELP - Ms Anna MEDARSKA-LAZOVA, Directorate General Human Rights and Rule of Law

PARLIAMENTARY ASSEMBLY/ASSEMBLÉE PARLEMENTAIRE - Ms Dana KARANJAC, Secretariat of the Committee on Culture, Science, Education and Media

Ms Reina DE BRUIJN-WEZEMAN, member of the Committee on Social Affairs, Health and Sustainable Development

Ms Tanja KLEINSORGE, Head of Secretariat, Committee on Social Affairs, 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

CONFERENCE OF INGOS/ CONFÉRENCE DES OING - Mme Marie-José SCHMITT, vice-présidente de l'Action Européenne des Handicapés (AEH)

#### **OTHER PARTICIPANTS / AUTRES PARTICIPANTS**

#### Canada -

Holy See/Saint-Siège - Mgr Jacques SUAUDEAU

#### Japan/Japon -

Mexico/Mexique - Dr. Manuel H RUIZ DE CHÁVEZ, President of the Council of the National **Commission of Bioethics** 

#### USA/Etats-Unis d'Amérique -

Republic of Belarus - Ms 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 apologised/excusée

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

apologised/excusé

apologised/excusé

apologised/excusée

#### apologised/excusé

apologised/excusé

#### apologised/excusé

<u>World Health Organisation/Organisation Mondiale de la Santé (WHO/OMS)</u> - Dr Andreas REIS, Technical Officer, HIS/KER, Cluster of Health Systems and Innovation, World Health Organization <u>apologised/excusé</u>

EHESP - Mr Loïc MAIGNAN, Elève directeur d'hôpital

#### **OBSERVERS / OBSERVATEURS**

<u>KEK - Conference of European Churches/Conférence des Eglises Européennes</u> – Rev. Sören LENZ, Executive Secretary, Conference of Europeen Churches

INGOs

**<u>Rehabilitation International (RI)</u>** - Dr Régine ERNST - Project Manager on Rehabilitation and Foreign Affairs, Bundesarbeitsgemeinschaft für Rehabilitation e.V./Rehabilitation International (RI)

European Association of Service Providers for Persons with Disabilities (EASPD) - Mr Luk ZELDERLOO, Secretary General

Mr Josep Maria SOLÉ CHAVERO, Board member of EASPD

European Disability Forum (EDF) - Ms Marine ULDRY, European Disability Forum (EDF), Human Rights officer apologised/excuse

Mr Kristijan GRDAN, European Disability Forum (EDF)

Ms Jolijn SANTEGOEDS, European Disability Forum (EDF), European Network of Ex-Users and Survivors of Psychiatry

#### SECRETARIAT

#### DIRECTORATE GENERAL HUMAN RIGHTS AND RULE OF LAW HUMAN RIGHTS DIRECTORATE/ DIRECTION DES DROITS DE L'HOMME

Mr Christophe POIREL, Director/Directeur

#### 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 Lee HIBBARD, Administrator / Administrateur, Tel: +33 (0) 388 41 31 04, Email: lee.hibbard@coe.int

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Ms Myrto KARYDI, Trainee / Stagiaire, Tel: +33 (0) 388 41 30 05, Email: Myrto.karydi@coe.int

# **INTERPRETERS / INTERPRETES**

Mrs Sally BAILEY-RAVET Ms Amanda BEDDOWS Mr Grégoire DEVICTOR

# Appendix II Agenda/order of business

Tuesday 19 November 2019 (9.00 – 18.00)		
	1. Adoption of the draft agenda	
To be dealt	<ul> <li>2. Developments in the field of bioethics</li> <li>Delegations, including observers, are invited to send information in writing.</li> <li>a. Developments in member states and other states</li> <li>b. Developments in the field of bioethics in international organisations</li> </ul>	
with in writing	<ul> <li>c. Relations with other international organisations: list of meetings</li> <li>d. Developments in other Council of Europe bodies</li> <li>e. Developments at the European Court of Human Rights</li> </ul>	
To be dealt with in writing	3. 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 Purpose	
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	4. Strategic Action Plan	
	<ul> <li>Presentation of the draft Strategic Action Plan revised by the Drafting Group</li> <li>Discussion on the draft Strategic Action Plan with a view to its adoption and presentation to the Steering Committee on Human Rights for approval</li> </ul>	
	<ul> <li>5. Additional Protocol on the protection of the human rights and dignity of person with regard to involuntary placement and involuntary treatment in mental health care <ul> <li>Presentation of the approach initiated at the Consultation meeting with a view to revising the draft Additional Protocol</li> <li>Discussion on whether the work initiated is going in the right direction</li> <li>Agreement on the working method to be followed</li> </ul> </li> </ul>	
	<ul> <li>6. Comments on PACE Rec 2158(2019) – "Ending coercion in mental health: the need of a human rights-based approach"</li> <li>Examination of the draft Prepared by the Secretariat with a view to its adoption and presentation to the Committee of Ministers</li> </ul>	
Ø	7. Study on good practices in mental healthcare - How to promote voluntary measures	
	<ul> <li>Information to be provided by the Secretariat on the preparation of the study.</li> </ul>	

Wednesday 20 November 2019 (9.00-18.00)		
	8. Question to the ECHR under Article 29 of the Oviedo Convention	
	<ul> <li>Presentation of the draft questions prepared by the Bureau in cooperation with the Secretariat</li> <li>Discussion on the draft with a view to a decision on a request to be addressed to the ECHR under article 29 of the Oviedo Convention</li> </ul>	
	9. Public debate	
	<ul> <li>Presentation of the revised draft Guide</li> <li>Discussion on the draft Guide to public debate with a view to its adoption</li> </ul>	
	10. Gender equality	
	<ul> <li>Designation of a new gender equality rapporteur</li> <li>Request for an introductory document on gender mainstreaming to be prepared by a consultant</li> </ul>	
	<ul> <li>11. Cooperation with other committees <ul> <li>a. European Committee on Organ Transplantation (CD-P-TO)</li> <li>b. European Committee on Blood Transfusion (CD-P-TS)</li> <li>c. Consultative Committee of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (T-PD)</li> <li>d. Ad Hoc Committee for the Rights of the Child (CAHENF)</li> </ul> </li> </ul>	
	12. Cooperation activities	
Ø	<ul> <li>Information by the Secretariat on current and future activities</li> </ul>	
Thursday 21 November 2019 (9.00- 13.00)		
	13. Bureau election	
	<ul> <li>Delegations are invited to proceed to:</li> <li>Election of the Chair and Vice-Chair of the Committee for a one-year term</li> <li>Election of a new Bureau member (after the departure of Prof. Constantinos Phellas) for a two-year term, renewable once</li> </ul>	
	Submission for nominations should be sent in writing to the Secretariat by <u>14.00 on Wednesday 20 November 2019.</u>	

14. Presentation of the studies on genome editing and exchange with delegations
<ul> <li>Presentation of developments in genome editing technologies and the ethical issues they raise, by</li> <li>Prof. Heidi Howard (Uppsala University, Sweden)</li> <li>Prof. Ian Toma (George Washington University, USA)</li> <li>Exchange of views with the delegations</li> </ul>
15. Dates of the next meetings
Dates proposed: - 17 <sup>th</sup> meeting of the DH-BIO: 2-5 June 2020 - 18 <sup>th</sup> meeting of the DH-BIO: 3-6 November 2020
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16. Decisions taken by the DH-BIO at its 16 <sup>th</sup> meeting
- Approval of the list of decisions
17. Other business
<ul> <li>Impact of Rec(2016)8 on the processing of health related data for insurance purposes, including data resulting from genetic testing.</li> </ul>