# ADVANCING HUMAN RIGHTS IN BIOMEDICINE

# Public debate as a tool for the governance of new technologies



# **High-level seminar**

organised by the Committee on Bioethics (DH-BIO) of the Council of Europe under the auspices of the French Presidency of the Committee of Ministers 4 June 2019 Room 1, Palais de l'Europe, Strasbourg







#### **TUESDAY 4 JUNE 2019**

#### **OPENING**

#### 9.15-10.00 Opening remarks

#### Chair

**Tesi Aschan** (Sweden), Chair, Committee on Bioethics (DH-BIO), Council of Europe

- ► Thorbjørn Jagland, Secretary General, Council of Europe
- ▶ **Brigitte Bourguignon,** President, Social Affairs Committee, National Assembly (France)
- ► Liliane Maury Pasquier (Switzerland), President, Parliamentary Assembly, Council of Europe

#### PUBLIC DEBATE AT THE NATIONAL LEVEL

#### Moderators

**Anne Forus**, Directorate of Health (Norway) **Marie-Hélène Mouneyrat**, National Consultative Ethics Committee (France)

**10.00-10.30** Introductory remarks by **Jean-François Delfraissy**, President, National Consultative Ethics Committee (CCNE), (France)

#### 10.30-11.00 Coffee break

**11.00-12.30** Public debate in action at the national level – why, what and when?

#### **Panellists**

Simon Burall, Involve (United Kingdom)

Rodica Gramma, University of Medicine and Pharmacy (Moldova)

Lars Klüver, Danish Board of Technology Foundation (Denmark)

Karine Lefeuvre, EHESP School of Public Health (France)

Solvita Olsena, University of Latvia (Latvia)

**Paula Martinho Da Silva**, Former President of the National Council of Ethics for Life Sciences of Portugal, member of the International Bioethics Committee (UNESCO)

#### PUBLIC DEBATE AT THE INTERNATIONAL LEVEL

#### Moderator

Peter Mills, Nuffield Council on Bioethics (United Kingdom)

14.30-14.45 Introductory remarks by **Stefan Schennach** (Austria), Rapporteur on "New forms of public debate on the ethical aspects of the rapid advancements in science and technology", Committee on Culture, Science, Education and Media, Parliamentary Assembly of the Council of Europe

**14.45-16.15** Public debate, human rights and the international governance of biomedicine

#### **Panellists**

Jim Dratwa, Ethics in Science and New Technologies, European Commission

**Dafna Feinholz**, Bioethics and Ethics of Science Section, UNESCO **Benjamin Hurlbut**, Arizona State University (USA)

Andreas Reis, Global Health Ethics, WHO

**Mariachiara Tallacchini**, Catholic University of the Sacred Heart (Italy) **David Winickoff**, Science and Technology Policy Division, OECD

#### 16.15-16.45 Coffee break

**16.45-17.00** Governance of new technologies and public debate – what strategic action for the Council of Europe?

**Siobhán O'Sullivan** (Ireland), Chair of the DH-BIO Drafting Group on the Strategic Action Plan for 2020-2025

#### **CONCLUSIONS AND NEXT STEPS**

#### 17.00-17.30 Concluding remarks and next steps

- ▶ Olivier Becht (France), General Rapporteur on Science and Technology Impact Assessment, Committee on Culture, Science, Education and Media, Parliamentary Assembly of the Council of Europe
- ▶ **Jean-Baptiste Mattei**, Ambassador, Permanent Representative of France to the Council of Europe
- ► Tesi Aschan (Sweden), Chair, Committee on Bioethics (DH-BIO) of the Council of Europe

# BIOGRAPHICAL NOTES

# Thorbjørn Jagland

#### Secretary General, Council of Europe



Mr Thorbjørn Jagland was elected Secretary General of the Council of Europe in September 2009. In June 2014, he was re-elected, and his second term in office commenced on 1 October, 2014.

He was the President of the Storting (Norwegian Parliament) from 2005 to 2009.

He is a member of the Norwegian Nobel Committee, which awards the Nobel Peace Prize every year.

He has held two of the most influential governmental positions in Norway: Prime Minister (1996-97) and Minister of Foreign Affairs (2000-2001).

After serving as Foreign Minister, he was Chairman of the Standing Committee on Foreign Affairs and the enlarged Foreign Affairs Committee in the Storting for four years (2001-2005). He also served as Chairman of the EEA Consultative Committee during this period (2000-2005). In addition, he has held a number of other parliamentary positions, such as head of the Storting's Delegation for Relations with the European Parliament for six years. He was a member of the Storting for 15 years.

Mr Jagland was Leader of the Norwegian Labour Party for ten years (1992-2002), and Party Secretary of the Labour Party for five years (1987-1992). He is currently the Chairman of the Board of Directors at the Oslo centre for Peace and Human Rights, and Member of the International Board of Governors at the Peres Center for Peace.

He served as Vice-President of the Socialist International 1999-2008, and Chair of the Social International Middle East Committee from 2000 to 2006. He was a member of the Sharm El-Sheikh Fact-finding Commission (The Mitchell Commission) from 2000 to 2001.

Over the last 20 years, Mr Jagland has published widely on a range of issues, in particular on European and international affairs. He has published four books in Norway: My European Dream (1990), Letters (1995), Our Vulnerable World (2001) and Ten Theses on the EU and Norway (2003). He holds a degree in Economics from the University of Oslo (1975). He was born on 5 November 1950 in Drammen, Norway. He is married to Hanne Grotjord. They have two children.

# Brigitte Bourguignon, President, Social Affairs Committee, National Assembly (France)



Brigitte Bourguignon (born on the 21th of March 1959 in Boulogne-sur-Mer) began her career as a medical secretary before joining the territorial administration. Firstly, responsible in the services of Boulogne-sur-Mer, she was in charge of voluntary aid to people and the establishment of minimum income and integration, she then joined the General Council of Pas-de-Calais responsible for the monitoring of City policies and contracts.

In 2001, she became deputy mayor of Boulogne-sur-Mer, in charge of health, early childhood and the accessibility of the City for persons with disabilities.

In 2012, after serving as National Secretary of Sports for the Socialist Party, Brigitte Bourguignon was elected as a Member of the National Assembly for the 6th constituency of Pas-de-Calais, and became a member of the Committee on Cultural Affairs and Education and the Delegation of Women's Rights. Appointed Chair of the High Council of Social Work in 2016, she was re-elected deputy of Pas-de-Calais in 2017 and currently chair's the Social Affairs Committee of the National Assembly.

Very engaged in the field of associations, she founded three structures of social and professional integration in Boulogne-sur-Mer and is involved in defense of the right to die with dignity.

# Liliane Maury Pasquier

#### President, Parliamentary Assembly, Council of Europe



Born Geneva 1956

#### Political experience

Since 2007: Councillor to the Council of States (Swiss Parliament) – Socialist Party

In Strasbourg: Member of the Swiss Delegation to the Parliamentary Assembly of the Council of Europe (2011-2013: Chair of the Delegation); Former president of the Socialists, Democrats and Greens' Group (January-June 2018); Former chair of the Rules

Committee (2016-2018); Former Chair of the Committee on Social Affairs, Health and Sustainable Development

In Berne: Former chair of the Committee for Social Security and Public Health in the Council of States (2013-2015); Member of the Committee for Foreign Affairs of the Council of States; Chair of the Delegation for the Relations with the French Parliament

1995-2007: Councillor to the National Council (Swiss Parliament) – Socialist Party

In Berne: Chair of the Council and of the Federal Assembly in 2002; Member of the Committees for Social Security and Public Health, for Foreign Affairs, for Science, Education and Culture and for the Political Institutions; 1993-1996: Member of the Grand Council (Cantonal Parliament) – Socialist Party

In Geneva: Member of the Committees for Planning, for Health and Environment; 1983-1991: Municipal Councillor (Local Parliament) – Socialist Party

In Veyrier (Geneva): Chair of the Municipal Council in 1989 and 1990; Member of the Committees for Town Planning, for Youth and for Budget

#### Professional experience

Since 1989: independent midwife

2009-2013: Chair of the Swiss Federation of Midwives, Berne

# Tesi Aschan

# Chair, Committee on Bioethics (DH-BIO), Council of Europe



Tesi Aschan (jur.kand.) works as a senior legal adviser for the National Board of Health and Welfare in Sweden. Her main areas include the legislation on organs, tissues and cells, medical devices, assisted reproduction technology, genetic tests and end of life treatment.

Tesi Aschan has been on the Committee on Bioethics (DH-BIO) since 2012, and is a member

of its Bureau since 2015. She is currently the Chair of DH-BIO.

# **Anne Forus**

#### **Directorate of Health (Norway)**



Anne Forus is a Senior Adviser at the Norwegian Directorate of Health. She works mainly on ethical, legal and scientific /medical issues related to biomedicine and the application of biotechnology in health care and biomedical research. Her field of knowledge cover issues related to the use of genetic analyses, assisted reproduction technologies, prenatal diagnosis, pre-implantation genetic diagnosis, biobanks in research, and the use of tissues, cells and

organs.

Anne has been a delegate to DH-BIO/CDBI since 2003. She was Vice Chair in 2012 and Chair in 2013 and 2014.

Anne was appointed as member of the UNESCO International Committee on Bioethics (IBC) from 2016-2019.

Anne has a PhD in molecular biology and background in cancer research. She has published a number of scientific papers in peer-review journals and a book on ethical issues related to assisted reproduction technologies.

# Marie-Hélène Mouneyrat

#### **National Consultative Ethics Committee (France)**



- Master in Public Law
- ► Former student of the Institute of Political Studies of Paris (Science Po)
- Secretary General of CCNE since 1986 under the presidency of:
- Professor Jean Bernard (from 1986 to 1992)
- Professor Jean-Pierre Changeux (from 1992 to 1998)
- Didier Sicard (from 1998 to 2008)
- Alain Grimfeld (from 2008 to 2012)
- Jean Claude Ameisen (from 2012 to 2016)
- Jean-François Delfraissy (since 2017)

Responsible at the CCNE for "Young people" workshops on bioethics. Student Forums.

Participation in "Meeting of Minds". Deliberations of european citizens on neuroscience. 2006.

Participation and organization at the end-of-life citizen conference, organized by CCNE. 2013.

Representative of France, appointed by the Ministry of Foreign Affairs, to the Council of Europe's Committee on Public Debate.

Representative of CCNE in the Commission of Neonatal Diagnosis, DGS.

CCNE representative on the Homo Donor Commission, DGS.

# Jean-François Delfraissy

#### **National Consultative Ethics Committee (France)**



Jean-Francois Delfraissy is President of the National Consultative Ethics Committee (CCNE) in France since January 2017. Immunologist, he is a specialist in HIV and emerging viruses. He was Director of ANRS (France Recherche Nord&sud Sida-hiv Hépatites) and ITMO I3M (Aviesan-Inserm) until the end of 2016. In 2014, he was appointed inter-ministerial coordinator for the response to the Ebola epidemic. He was Head of the Department of Internal Medicine at the University Hospital Paris Sud (AP-HP), and Professor at the

University of Paris Sud Saclay.

Prof. Delfraissy has chaired several international scientific councils on HIV/AIDS as well as a series of international conferences devoted to infectious disease research such as the IAS World Conference in July 2017 in Paris. He has published more than 500 articles in the fields of immunology, internal medicine and HIV infection. He has established close collaborations with the HIV community both in France and in the South. Prof. Delfraissy was appointed Officer of the National Order of the Legion of Honour in 2010.

In 2018, as President of the CCNE, he led the Etats généraux de la bioéthique, which gave rise to a synthesis report and an opinion from the Committee. These documents are intended to inform French decision-makers responsible for revising the Bioethics Act, which will be adopted in 2019.

#### Simon Burall

#### **Involve (United Kingdom)**



Simon Burall is a Senior Associate of Involve. He has long and extensive experience in the fields of democratic reform, open government, public participation, stakeholder engagement, accountability and transparency, scientific and technology innovation and organisational change. He has worked at the local and national level in Africa, Asia and Europe as well as on related issues of global governance and democracy. His current role will see him leading an expansion of Involve's work on science and technology. This Citizens and Science programme will focus on developing more

effective ways for citizens to be involved in the development and application of new technological innovations with a particular focus on data and artificial intelligence.

In his role with Involve, Simon has worked with and advised many organisations including Number 10, the Cabinet Office, the Scottish Government, the Department for Business Innovation and Skills, the Department for Communities and Local Government, the Department of Health, the Department for Energy and Climate Change, NHS England, the UK Civil Society Network on Open Government, UNDP, OECD, the World Bank, the European Economic and Social Council, as well as at local level with numerous local authorities and other public bodies.

Simon has published extensively on issues related to democracy, participation, accountability and transparency.

Simon is the Programme Director for the Sciencewise Programme and a Fellow of WWF UK. He was a trustee and member of Council for Voluntary Services Overseas from 1997-2007, and a Trustee and Chair of Democratic Audit, 2008-2014.

Simon was Director of Involve from 2009 - 2017. Before moving to Involve Simon was a Research Fellow at ODI from 2006 - 2009. His interests included stakeholder engagement in the reform of the international aid delivery system and the effectiveness of development finance. Prior to this he was the Executive Director of the One World Trust from 1999 - 2005 where he initiated and oversaw the development of the influential Global Accountability Index. Simon has taught English in Namibia and science in Zimbabwe, and was an election monitor in Bosnia Herzegovina after the Dayton Agreement.

Simon has a BA in Natural Sciences and a PGCE from Cambridge University, and an MSc in Development Studies from SOAS.

#### Rodica Gramma

#### University of Medicine and Pharmacy (Moldova)



Rodica Gramma is associate professor of the School of Public Health Management at "Nicolae Testemitanu" State University of Medicine and Pharmacy, Republic of Moldova.

She graduated from the Faculty of Medicine in 1999, has the degree of Master in Bioethics (2001) and received her PhD degree (Philosophy of Science) in 2005 in Chisinau, Republic of Moldova. She completed the Advanced Certified Program in Research Ethics at Graduate College of Union University, Schenectady,

NY, USA (2007) and the Master in Health Law and Management at the Institute Catholique de Rennes/Université Montpellier, France (2013).

She joined the DH-BIO as a member in 2010 and in November 2018 was elected as DH-BIO Bureau member.

She also is an Ethics Expert H2020, DG Research & Innovation, Ethics and Research Integrity Sector, European Commission (2015 – present) and the member of the National Ethics Committee for Clinical Trials in Moldova.

Rodica teaches courses in Human Rights and Health Legislation; Bioethics; Public Health Ethics, Institutional Ethics Management; Research Ethics; Communication in Health. She participated in European and national research projects; is the author and co-author of several scientific papers, books and book chapters on Bioethics, Human Rights in Health and Public Health issues.

# Lars Klüver

#### **Danish Board of Technology Foundation (Denmark)**

Lars Klüver is director at the Danish Board of Technology Foundation (Fonden Teknologirådet, DBT). He has more than 30 years of experience in technology assessment (TA), foresight and Responsible Research and Innovation. His main focus has been on providing policy advice and solutions to societal challenges through dialogue and engagement involving representatives from societal groups, such as experts, stakeholders, politicians, citizens, users, etc.

The DBT has been a front-runner within policy analysis that involves interactivity, dialogue and participation, and the toolbox of the DBT includes a wide range of engagement methods, of which several been developed or adapted by the Board.

Lars Klüver has been active in policy analysis and participation research, for example as coordinator of the EUROPTA, CIVISTI, DESSI, PACITA, Engage2020, CIMULACT and EC02 projects, and he was the initiator of the "World Wide Views" initiative – a global citizen participation method, which has engaged more than 80 countries and is directed towards policymaking across geographic borders.

# **Karine Lefeuvre**

#### **EHESP, School of Public Health (France)**



Professor at the School of Advanced Studies in Public Health and Deputy Director of the Department of Humanities and Social Sciences, Karine Lefeuvre works particularly on the issues of the rights of vulnerable individuals, ethics and democracy in the health sector.

She is a qualified person at the High Council for the Family, Childhood and Age, in the Age division and a member of the Standing Committee to combat abuse and to promote well-treatment. She has been a

member of the National Ethics Advisory Committee since December 2017 and Vice President since February 2019. She is the co-director of the book "La démocratie en santé en questions" and "Protéger les majeurs vulnérables" (3 volumes) in the presses of the EHESP.

The forthecoming book to appear "Place à l'éthique" will appear in autumn 2019.

# Solvita Olsena

#### University of Latvia (Latvia)



Solvita Olsena is a health law expert with long experience both in academia and in legal practice. She is an associate professor of public health and law at the Medical Faculty, the University of Latvia where she teaches and writes in health law. Her academic interests and research topics include patients' rights and patient safety, medical data protection and eHealth, right to health and health inequalities. She is a sworn advocate and a member of the Latvian Collegium of Sworn Advocates. She holds a M.D. from the Medical Academy of Latvia, a J.D. and Dr.iur. form

the University of Latvia.

#### Paula Martinho Da Silva

#### Member of the International Bioethics Committee, UNESCO



- Law Degree, Faculty of Law, Classic University of Lisbon
- Master in Bioethics, Faculty of Medicine, Complutense University of Madrid
- Senior Researcher of Portuguese Catholic University (Bioethics Institute).
- Practising lawyer (since 1984) expertise on intellectual property and life sciences

In 1986, when she published her first book - "The Artificial Procreation - Legal Aspects" (collection of law

books, Moraes Editores).

Actually Paula is member of the UNESCO IBC (International Bioethics Committee);

And is member of the Ethics Committees of Champalimaud Foundation; Centro Hospitalar de Lisboa Central.

She has played several positions in the area of Life Sciences:

- Member of the European Group of Ethics in Science and New Technologies of the EU Commission 1998-2000; 2005-2010; 2011- 2016. Vice Chair 2004-2010.
- Chair of the National Council of Ethics for the Life Sciences CNECV (2003 2009).
- Member of the COMETH Bureau (European Conference of the National Councils of Ethics, Council of Europe (2003-2010).
- Member of the National Council of Ethics for the Life Sciences during two mandates (1991 2001).
- Member of the Scientific Committee of the International Society of Bioethics.

Recently, in November, 2018 she has been invited by the French Assemblée Nationale in which she was heard as an international qualified expert by the Commission for the revision of French bioethics laws.

In 2003 Paula was distinguished with the French decoration of "Chevalier de la Légion d'Honneur"

#### **Peter Mills**

# **Nuffield Council on Bioethics (United Kingdom)**



Pete Mills works at the intersection of emerging science, ethics and public policy. He is currently Assistant Director at the UK's Nuffield Council on Bioethics where he directs the Council's work programme on genome editing – see Genome editing: an ethical review (2016) and Genome editing and Human Reproduction: social and ethical issues (2018).

His latest project relates to genome editing in farmed animals; earlier work led to reports on Emerging Biotechnologies (2012) and Data in Biomedical

Research and Health Care (2015).

Pete is also currently a member of the World Economic Forum Global Future Council on Biotechnology and the Council of Europe working group on public debate and bioethics.

He has previously held positions at the UK Department of Health and the Human Fertilisation & Embryology Authority.

From 2007-10 he was head of the secretariat of the UK's Human Genetics Commission and was a member of the UK delegation to the Council of Europe Bioethics Committee (DH-BIO) in 2007-09 and 2015-16. Pete read PPE at Trinity College, Oxford, and has a PhD in philosophy from the University of Warwick.

# Stefan Schennach

Committee on Culture, Science, Education and Media, Parliamentary Assembly of the Council of Europe



Member of the Federal Chamber, Parliament, Austria

Member of the Council of Europe

Chair of the Committee for Future, Innovation and Science (in Austria) and vice-chair of the Committee for European questions

Chair of the Committee for Social, Health and Sustainable Development

Former chair of the Committee for Conflicts between Member States of the Council of Europe and the Monitoring Committee

Co-Rapporteur for Azerbaijan

8 years Chair of the Committee for Energy, Environment and Water of the Union for the Mediterranean

Member of COSAC

Many times head of observation mission in Macedonia

Rapporteur for dirty money and money laundry, youth in detention, illegal trafficking of cultural heritage

Head of fact finding mission in Jordan valley regarding water for Syrian refugees in Turkey and Jordan, special visit about the situation in prisons in Moldova

Author of books

Director of Austria Barocq Academie

#### Jim Dratwa

#### Ethics in Science and New Technologies, European Commission



Jim Dratwa's research addresses the role of public debate (what public? what debate?) in the making of normative and technological orders. More specifically: the interconnections between knowledge, values and action. He has served in several positions of responsibility in that regard at the European Commission, as member of BEPA (the Bureau of European Policy Advisers to the President), at the EPSC (the European Political Strategy Centre) and in the Directorate-General

for Research and Innovation.

At the European Commission, he heads the team tasked with Ethics in Science and New Technologies, he is the Secretary-General of the EC International Dialogue on Ethics and Bioethics, and the EC representative in the international organisations dealing with the ethical implications of science and new technologies.

His degrees are in physics, philosophy, politics and the life sciences; he received the Fulbright Scholar Award, was Harvard Boas Fellow, Ramón y Cajal Scholar, and was pre- and post-doctoral Fellow at Harvard Kennedy School of Government, in the Belfer Center for Science and International Affairs and with the program on Science, Technology, and Society.

He has taught at the Ecole des Mines de Paris, Sciences Po Paris, Harvard University, and the universities of Brussels, where he is currently based. He is also a Distinguished Scholar of the Woodrow Wilson Center, Washington, DC.

# Dafna Feinholz

#### **Bioethics and Ethics of Science Section, UNESCO**



Dafna Feinholz has a PhD in Research Psychology (UIA Mexico) and a Master in Bioethics (Universidad Complutense, Madrid, Spain).

She was the Head of the Reproductive Epidemiology Department at the Mexican National Institute of Perinatology, and the Research and Planning Director of the Women and Health Programme, at the Ministry of Health (Mexico). She successively occupied the posts of Academic Coordinator of the National Commission of Human Genome at the Ministry of

Health; and the Executive Director of the National Commission of Bioethics, achieving a more independent legal status for the National Bioethics Committees, co-drafing the mission of the NBC, which was defined as promoting a bioethics culture and providing the necessary elements to society and decision makers, to understand the ethical issues and how to approach them, rather than producing decisions.

Among the achievements are also drafting the first national guidelines for Research Ethics Committees and Clinical Bioethics Committees, training their members, and promoting the law at the Parliament that is currently in vigour, and that has established and differentiated both types of committees. She is the founder of FLACEIS (Latin American Forum of Ethics Committees in Health Research) and was the Chairperson (2000-2006). She was an Invited member of the international expert group, TDR-WHO: Drafting and translating Operational Guidelines for Ethics Committees. She was Mexico's representative at the meetings of the Intergovernmental Bioethics Committee to discuss the UNESCO Universal Declaration on Bioethics and Human Rights.

Since September 2009, Dafna Feinholz is the Chief of the Bioethics and Ethics of Science Section, within UNESCO Social and Human Science Sector. In this capacity, she leads different activities aiming at reinforcing capacities of Member States to manage bioethical challenges and to identify the ethical, legal and social implications of cutting-edge science, emerging technologies and their application for sustainable development, and promoting awareness raising and public debate.

# **Benjamin Hurlbut**

#### **Arizona State University (USA)**



J. Benjamin Hurlbut, PhD is Associate Professor of Biology and Society in the School of Life Sciences at Arizona State University.

He is trained in science and technology studies (STS) with a focus on the history of the modern biomedical and life sciences. Hurlbut studies the changing relationships between science, politics and law in the governance of biomedical research and innovation, examining the interplay of science and technology with notions of democracy, religious and moral pluralism,

and public reason.

He is the author of Experiments in Democracy: Human Embryo Research and the Politics of Bioethics (Columbia University Press, 2017) and co-editor of Perfecting Human Futures: Transhuman Visions and Technological Imaginations, (Dordrecht: Springer, 2016), as well as numerous articles and book chapters.

He received an A.B. in Classics from Stanford University and a Ph.D. in the History of Science from Harvard University. He was a postdoctoral fellow in the program on Science, Technology and Society at the Harvard Kennedy School.

# **Andreas Reis**

# Global Health Ethics, WHO



Andreas Alois Reis (MD, MSc) is the Co-Lead of the Global Health Ethics Team in the Division of the Chief Scientist at WHO in Geneva, Switzerland.

After medical studies and practice in internal medicine in Germany, France and Chile he pursued studies in health economics and obtained a post-graduate degree in biomedical ethics.

His main area of work is public health ethics, with a focus on ethics and infectious diseases.

He has lectured and organized trainings for WHO in more than 40 countries, has published widely and is the co-editor of three books on bioethics and public health ethics.

# Mariachiara Tallacchini

#### Catholic University of the Sacred Heart (Italy)



Mariachiara Tallacchini is professor of Philosophy of Law at the Faculty of Economics and Law, Università Cattolica del Sacro Cuore (Piacenza, Italy) and of Science, Law, and Democracy at the International School for Advanced Studies (SISSA, Trieste - Italy).

She earned a degree in Law and a PhD in Legal Philosophy (University of Padua), and worked as a postdoctoral fellow in the STS programme at the Kennedy School of Government (Harvard University), where she also attended the Centre for the Biology of

Transplant at MGH-Harvard Medical School, working on the regulatory aspects of xenotransplantation. She has been a consultant to the Italian Parliament and the Italian Commission of Bioethics, and collaborated with the WHO Regional Office of Rome on Environment and Health. Between 2007 and 2009 she has chaired the European Advisory Group on Science in Society for FP7. From 2013 to 2015 she worked as Senior Scientists at the European Commission Joint Research Centre (JRC, Ispra). Her interests concern the legal regulation of science and technology and the relationships between science and democracy, especially in the domain of the life sciences and their interfaces with ICT.

Among her publications: From Privacy to Algorithms' Fairness. In: M.Hansen, E.Kosta, I.Nai-Fovino, S.Fischer-Hübner (Eds.), Privacy and Identity Management. The Smart Revolution, Springer, Cham 2018, 86-110 (with C. Sabelli); Emerging ICT for Citizens' Veillance: Theoretical and Practical Insights. Special issue. Science & Engineering Ethics 2018, 24:821-1021 (with P. Boucher and S. Nascimento); Medical Technologies and EU Law: The Evolution of Regulatory Approaches and Governance, in M. Cremona (ed.), New Technologies and EU Law, 2017; Risks and Rights in Xenotransplantation, in Sheila Jasanoff (ed.), Reframing Rights. Bioconstitutionalism in the Genetic Age, MIT Press, Cambridge MA 2011, 170-192; Università Cattolica S.C., Facoltà di Economia e Giurisprudenza, Parmense 29122 Piacenza Emilia 84. (Italv). Email: mariachiara.tallacchini@unicatt.it

# **David Winickoff**

#### Science and Technology Policy Division, OECD



David E. Winickoff, JD, MA, is Senior Policy Analyst and Secretary of the Working Party on Bio-, Nano- and Converging Technology at the Organization for Economic Cooperation and Development (OECD) in Paris. He also currently serves as Visiting Professor of Law at L'Institut d'études politiques de Paris (Sciences Po). He came to the OECD from a tenured professorship in bioethics and biotechnology policy at University of California, Berkeley, where he directed the Program in Science and Technology Studies for four years and wrote widely in the areas of genomics policy,

technology transfer, science and democracy, and international trade law.

At the OECD, he leads international work advancing the responsible development of emerging technologies in areas such as synthetic biology, neurotechnology, gene editing, the bioeconomy, and convergent production technologies such as robotics and cyber-physical systems.

He has over fifty publications in academic journals and other outlets, e.g. Science, New England Journal of Medicine, Nature Climate Change, and the Yale Journal of International Law. Winickoff has served as a working group member and co-author at the U.K. Royal Academy, the U.S. National Academies of Science, and the Bipartisan Policy Center. He was a Greenwall Scholar in Bioethics from 2010-2013. He holds degrees from Yale University, Cambridge University, and Harvard Law School and was a fellow for two years at the Harvard Kennedy School in Science and Technology Studies.

# Siobhán O'Sullivan

Chair of the DH-BIO Drafting Group on the Strategic Action Plan for 2020-2025, Council of Europe



Prof. Siobhán O' Sullivan is the Chief Bioethics Officer at the Department of Health and is responsible for drafting policy advice and legislative instruments on bioethics related issues. She is also Professor in the Royal College of Surgeons Ireland, where she teaches Healthcare Ethics and Law and is involved in curriculum development.

From 2002-2010, Prof. O'Sullivan was Director of the Irish Council for Bioethics an independent, autonomous body to consider the ethical issues raised by

developments in science and medicine.

She is the vice-chair of the European Group on Ethics in Science & New Technologies, an independent, multidisciplinary body advising the European Commission in connection with Community legislation or policies. She is a former member of the Advisory Council for Science, Technology and Innovation, the Irish Government's high-level advisory body on Science, Technology and Innovation (STI) policy issues.

She received her Doctor of Medicine from Karolinska Institutet, Stockholm in 1998 and hold a Masters in Healthcare Ethics and law and a Masters in Human Rights Law.

# **Olivier Becht**

# Committee on Culture, Science, Education and Media, Parliamentary Assembly of the Council of Europe

Olivier Becht (born 1976) is a French representative, first elected at the Assemblée Nationale in 2017. He is also former Mayor of the city of Rixheim (15000 inhabitants, 2008-2017), President delegate of Mulhouse Alsace Agglomeration (chairman of the commission on economic development and attractiveness, 2010-2017) and Vice-President of the Department Haut-Rhin (in charge of local law and economy, 2015-2017).

After his graduation from Sciences Po Strasbourg and the University Panthéon-Assas in Paris with a Master's degree in public finance, he entered the Ecole Nationale d'Administration (2002-2004, Promotion Léopold Sédar Senghor, the same as the French President Emmanuel Macron).

As Vice-President of the French delegation at the Parliamentary Assembly of the Council of Europe, his specific interests are the evolution of mankind and people throughout the electronic and technologic revolution. He thus is a full-member of the Committee of Culture, Science, Education and Media and the sub-committee on media and information society.

His interests in these fields lead Olivier Becht to write parliamentary reports for the French Assemblée Nationale on the digitalization of the army and on the evolution of spatial defense as a member of the Commission for National Defense and Armed Forces, for which he got recognition from his peers for these questions of technological evolution in the next years.

He became General Rapporteur on science and technology assessment in 2019 for the Council of Europe Parliamentary Assembly, with a particular attention on bioethics and the way the Great Europe will have to deal with the NBIC (nanotechnology, biotechnology, information technology and cognitive science), facing the other worldwide powers.

# Jean-Baptiste Mattei

# Ambassador, Permanent Representative of France to the Council of Europe



Born in 1958 Married, 3 children

Graduate, Faculty of Law of the University of Paris Graduate of Ecole des Hautes Etudes Commerciales (1979) and Ecole Nationale d'Administration (1983)

Chevalier de l'Ordre National du MériteChevalier de la Léaion d'honneur

2013 - 2016 Ambassador,

Permanent

Representative of France to NATO

2012 - 2013 Director general for Global Affairs, Development and Partnerships – Ministry of Foreign Affairs

2007 - 2012 Ambassador and Permanent Representative of France to the UN and other International Organizations in Geneva

2005 - 2007 Director, Department of Information and Communication, Spokesperson of the Ministry of Foreign Affairs

2004 - 2005 Director, Office of the Minister for European Affairs

2000 - 2004 Deputy Permanent Representative of France to the North Atlantic Treaty Organization – Brussels

1995 - 2000 Director, Division of EU External Relations - Ministry of Foreign Affairs

1991 - 1995 Counsellor, Permanent Representation to the EU – Brussels

Office of the Secretary of State for Foreign Affairs 1989 - 1991

1988 - 1989 Office of the Prime Minister

1985 - 1988 First Secretary, Embassy to the Arab Republic of Egypt -Cairo

1983 - 1985 Directorate general for Administration – Ministry of Foreign

Affairs

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