KICK-OFF MEETING

International Association for Responsible
Research and Innovation In Genome Editing

FRIDAY MARCH 23, 2018
PARIS

On March 23rd we will launch the international Association for Responsible Research and Innovation in Genome Editing (ARRIGE) to promote a global governance of genome editing. We aim at providing a comprehensive setting for all stakeholders (academics, private companies, patient organizations, citizens, decision makers) to allow the development of these paramount technologies in a safe and socially acceptable environment. This meeting is the continuation of several workshops held with African, Latino-American and Indian colleagues, to find common means to address the ethical and societal issues raised by the rapid introduction of gene editing technologies.

http://arrige.org

Région Île-de-France
Paris
France

Steering committee:
Jennifer Merchant, Marion Abecassis, Bernard Baertschi, Hervé Chneiweiss, François Hirsch, Pierre Jouannet, Lluis Montoliu, Cyril Sarrauste de Menthière

SUMMARY

WORKSHOP PROGRAMME

9:30-10:00	**Registration of participants**	
10:00-10h30	**Welcome addresses**	**Hervé Chneiweiss** (president, Inserm Ethics Committee) **Faten Hidri** (vice-president High Education & Research, Région Île-de-France) **Lluis Montoliu** (CNB-CSIC and CIBERER-ISCIII)
	Introductory lectures *Chair:* **Jennifer Merchant** (Inserm ethics committee & Univ. Panthéon-Assas, Paris)	
10:30-11:00	**Setting the stage, where do we stand today with CRISPR technology**	**Francisco J.M. Mojica** (Univ. of Alicante, Madrid) introduced by **Lluis Montoliu** (CNB-CSIC and CIBERER-ISCIII)
11:00- 11:30	**Coffee break**	
11:30- 12:00	**Review of ethics positions, reports, documents published on gene editing by other groups and institutions**	**Ewa Bartnik** (Univ. of Warsaw, former rapporteur UNESCO IBC)
12:00-12:15	**Taking seriously the anthropological and societal impact of genome editing technologies**	**Mylène Botbol-Baum** (Inserm Ethics Committee & Catholic Univ. of Louvain, Brussels)
12:15-12:45	**Ethics of the genome editing technologies: presentation of ARRIGE**	**Hervé Chneiweiss** (Inserm Ethics Committee)
12:45-14:00	**Lunch break**	

	Addressing issues raised by GE technology through the creation of ARRIGE *Chairs:* **Marion Abecassis** (Inserm ethics commitee), **Paul-Loup Weil-Dubuc** (Espace éthique Île-de-France, Paris Saclay Univ.)	
14:00-14:25	**Human issues**	**Peter Mills** (Nuffield Council on Bioethics, UK)
14:25-14:50	**Environmental issues**	**Andreas Kurtz** (Charity Hospital Berlin, European Group on Ethics)
14:50-15:15	**Animal issues**	**Filipa Ferraz de Oliveira** Ethics Sector (European Research Council, Brussels)
15:15-15:40	**Intellectual properties & economic issues**	**Béatrice Holtz** (LAVOIX, Paris)
15:40-16:05	**Involving patients in the discussion**	**Lauren Roberts** and **Louise James** (Genetic Alliance UK)
16:05-16:30	**Workshop conclusion: next steps**	**Lluis Montoliu** (CNB-CSIC and CIBERER-ISCIII)
16:30-17:00	**Final comments**	**Yves Lévy** (CEO, Inserm) **Magnus Magnusson** (director Partnership and Outreach, SHSS, UNESCO)

PRESENTATION OF PARTICIPANTS/STEERING COMMITTEE MEMBERS

Marion **ABECASSIS**

Bernard **BAERTSCHI**

Ewa **BARTNIK**

Mylène **BOTBOL-BAUM**

Hervé **CHNEIWEISS**

Filipa **FERRAZ de OLIVEIRA**

Faten **HIDRI**

François **HIRSCH**

Béatrice **HOLTZ**

Louise **JAMES**

Pierre **JOUANNET**

Andreas **KURTZ**

Yves **LÉVY**

Magnus **MAGNUSSON**

Jennifer **MERCHANT**

Peter **MILLS**

Francisco J.M. **MOJICA**

Lluis **MONTOLIU**

Lauren **ROBERTS**

Cyril **SARRAUSTRE de MENTHIÈRE**

Paul-Loup **WEIL-DUBUC**

Marion Abecassis

Marion Abecassis is an attorney-at-law admitted to practice in Paris and New York, focusing her practice in life sciences and having a special interest in bioethics. She assists French and international health care stakeholders at the Paris office of McDermott, Will & Emery. In parallel, she follows the work of the Inserm Ethics Committee and has regularly participated in its activities since April 2016. Finally, she chairs the first instance disciplinary commission on doping of the French Disabled Sports Federation since July 2017. She holds a masters in health law from Université Paris-Descartes (France) and a Masters in global health law from Georgetown University (United States) under a Fulbright Grant 2014.

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Bernard Baertschi

Bernard Baertschi graduated from the University of Fribourg (Switzerland) and obtained his doctoral degree in philosophy at the University of Geneva in 1979. After having taught in a secondary school during some years, he joined the Department of philosophy at the University of Geneva, and then the Medical faculty. He is now retired. He was visiting scholar at several universities in Switzerland and France (Grenoble). His doctoral dissertation was dedicated to a French philosopher from the post-enlightenment, Maine de Biran, but he was soon interested in moral philosophy and bioethics, the topics that were at the center of his teaching and his researches since then. He published several books on these topics, particularly on the ethics of biotechnologies (genetic engineering and medically assisted procreation), of synthetic biology and of neurosciences. He was a member of the Swiss Committee on Animal Experimentation (2000-2011), of the Federal Ethics Committee on Non-Human Technology (2002-2015), and is presently member of the Inserm Ethics Committee (Paris).

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Ewa Bartnik

Ewa Bartnik is Professor of genetics at the University of Warsaw and the Institute of Biochemistry and Biophysics, Polish Academy of Sciences. Current research interests: role of mitochondria in human diseases and aging; previous: biochemical genetics of *Aspergillus nidulans*, DNA methylation, regulation of gene expression in mitochondria, mitochondrial DNA mutations in cancer. She coordinated the program to reform the science curriculum in Polish schools in 2008 and is active in popularizing science. Member of the Bioethics Committee of the Praesidium of the Polish Academy of Sciences since 2015. Member of the UNESCO International Bioethics Committee 2010-2017, rapporteur 2015-2017. Member of the PISA Science Expert Group 2006-2009.

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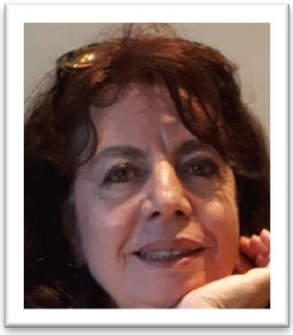
Mylène Botbol-Baum



Mylène Botbol-Baum has a PhD in philosophy from Marquette University (USA). She is Professor of philosophy and bBioethics in the faculties of Medicine, Philosophical Sciences, and Public Health of the UCL (Université catholique de Louvain) in Brussels, Belgium. She is responsible for the Center for Bioethics HELESI (Health, Ethics, Law, Economy and Social Issues, see https://uclouvain.be/fr/instituts-recherche/irss/helesi). She is a founding member of the research group Center Europe at the Institute of Philosophy (UCL), member of the Geneva University Ethical Committee since 2010 (renewed twice), member of the Inserm Ethics Committee since 2013, and was a member of the Belgian Advisory Committee on Bioethics from 2011 to 2014. She has authored more than 150 academic papers and several books on bioethics and on philosophy.

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Hervé Chneiweiss

Hervé Chneiweiss is a neurologist and neuroscientist, MD-PhD, Research Director at the CNRS. First trained as a neurologist (gait and movement disorders, Parkinson), he was involved in the neurogenetics of human diseases such as cerebellar ataxias. For the last 15 years his scientific work was dedicated to the biology of astrocytes and their roles in brain tumour origin and progression. Technical approaches include proteomics, metabolism, epigenetic, cell cultures, and animal models. He has authored more than 140 academic papers and several books for the lay public on neurosciences and bioethics.
He is currently head of the research centre Neuroscience Paris Seine – IBPS (CNRS UMR8246/Inserm U1130/Sorbonne University) and PI of Glial Plasticity team. He is also involved in bioethics, once (April 2000 to April 2002) the adviser for life sciences and bioethics to the French Minister for Research and Technology and presently head of the Inserm Ethics Committee, member of the French National Consultative Ethics Committee (CCNE, 2013-2017) and of the International Committee of Bioethics of UNESCO since 2013. He was also chief editor of *Médecine/Sciences* (2006-2016).

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Filipa Ferraz de Oliveira

Maria Filipa Ferraz de Oliveira has a PhD in medicine from the New University of Lisbon in Portugal. After having worked for several years as a Medical Doctor, in 1993 she advanced her academic career from Assistant Professor specialized in epidemiology and tropical health at the New University of Lisbon, including two years in Mozambique, to Head Health Sciences Department in 2004. She has also been Professor in epidemiology, environmental health and community health at the Lisbon School of Health Technologies. For the past 14 years, she has worked in the European Commission, in the DG for Research as Scientific Officer and now as Head of sector for ethics at the European Research Council Executive Agency (ERCEA), contributing to the organisation of the ethical screening and review procedures of research projects under FP7 and H2020.

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Faten Hidri

Regional councillor since 2010 and local councillor to the city Draveil since 2014, as lawyer Faten Hidri follows the questions of cooperation for her political formation. She is in charge of higher education and research within the Île-de-France Regional Council, a strategic sector for an attractive Region. Île-de-France covers 400 establishments of research and higher education, an essential domain for development, in particular with the Paris-Saclay project, which regroups 27 municipalities.

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François Hirsch

François Hirsch graduated with a degree in immunology from the Institut Pasteur and holds a certificate in science and medical ethics from Paris-Sud University; he is senior Research Director at Inserm. He spent several years as Seconded National Expert at the Governance and Ethics unit in the DG for Research of the European Commission where he helped in organising the ethics review of proposals, with a special focus on research conducted in LMICs. Returning to Inserm, he became Deputy Director of the Office for Clinical Research and Secretary General of the Inserm Ethics Committee. He then moved to the Institute for Health Technologies from the French National Alliance for Life Sciences and Health (Aviesan) where he is in charge of regulatory issues and ethics. He has been appointed as expert to evaluate the ethics of projects funded through FP7 and H2020. Since 2016, he has participated in the H2020 TRUST project (Creating and enhancing trustworthy, responsible and equitable partnerships in international research), which aims at providing the European Commission with recommendations for more virtuous research conducted in LMICs.

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Béatrice Holtz

Béatrice Holtz is a partner of the intellectual property firm LAVOIX. She joined LAVOIX in 2001, after receiving her MSc in engineering and Ph.D. in biochemistry from the French School of Life Sciences (Institut national agronomique Paris-Grignon). Her practice is focused on patent prosecution, client counseling, due diligence and freedom-to-operate studies, infringement opinions and litigation in the fields of biotechnology and pharmaceuticals. She represents a wide range of clients including public research institutes, large corporations and biotech startup companies.

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Louise James

Louise James is a volunteer Parent Representative for SWAN UK (syndromes without a name), the only specialist support network for families of children with undiagnosed genetic conditions in the UK. It is run by the charity Genetic Alliance UK. She has three children. Her youngest child Scott, who was born in 2010, has an undiagnosed genetic syndrome. Scott has complex epilepsy, severe learning difficulties, and global developmental delay but no overriding diagnosis to explain the cause of his issues. Prior to having children, Louise James worked in early years education and currently works part time as a special educational needs and disability support worker in a mainstream early years setting. She has volunteered as a Parent Representative for SWAN UK for approximately two years acting as local point of contact for families and professionals based in the South West of England. She is also a patient representative for the Rare Disease Clinical Oversight group of West of England Genomics Medicine Centre, which is responsible for delivering the 100,000 Genomes Project across the West of England.

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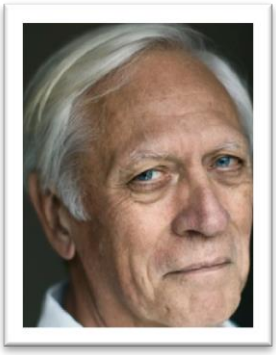
Pierre Jouannet



Pierre Jouannet is Professor Emeritus at the University Paris Descartes. His research activities have been focused on basic, clinical and ethical issues related to male fertility and reproductive assisted technologies. Head of the Reproductive Biology Department in Hôpital Cochin (Paris) from 1994 to 2007, he was the Chairman of the French Federation of CECOS (centers for the study and preservation of semen) and Vice-Chairman of the Medical and Scientific Committee of the Agence de la biomédecine. He is a member of the French National Academy of Medicine where he wrote the report on “Genome editing of human germline cells and embryos” published in 2016. He is also a member of the Inserm Ethics Committee.

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Andreas Kurtz

Andreas Kurtz has been since 2006 the Head of the Laboratory for Stem Cell Research and Knowledge Management at the Berlin-Brandenburg Center for Regenerative Therapies at Charity Hospital, Berlin (Germany), where his main interest lays in the development of cell therapies. He has been since 2007 coordinator of the European Human Pluripotent Stem Cell Registry (hPSCreg) and member of the European Group of Ethics since 2017. Previously he was Professor at the College of Veterinary Medicine at Seoul National University from 2009-2016 and between 2003 and 2006 Director of the German Authority for Stem Cell Research, Robert-Koch-Institute in Berlin. He was between 1995 and 2003 Assistant Professor for neurosurgery at Georgetown University, Washington DC and Harvard Medical School (USA). He was also CEO at several stem cell and genetic diagnosis companies. He received his PhD from the Central Institute for Molecular Biology, Academy of Science (German Democratic Republic) and his Diploma (MSc) in genetics from Martin Luther University Halle-Wittenberg

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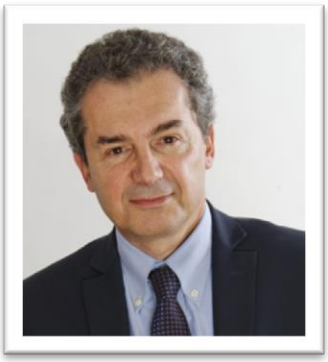
Yves Lévy



Pr Yves Lévy, MD, PhD, has been CEO and Chairman of Inserm since June 2014. He has also led since July 2014 Aviesan, the French National Alliance for Life Sciences and Health. He has developed research activity in several Inserm units since 1985. From 2007 to 2014, he led an Inserm team (U955 unit), “T cell development in Physiology and in HIV disease”, focused on HIV physiopathogenesis from upstream to translational researches in the field of immune interventions and vaccines. He served as the Director of the Inserm Unit 899 in Dallas (Texas, USA) from 2010 to 2012. Pr Lévy has created the “Vaccine Research Institute” (VRI) Labex. The VRI is aimed to face the challenges to develop effective vaccines against HIV. This research program is implemented by a large network of 17 teams and key international opinion leaders in this field from different institutions in France and the US through a unique collaborative network and with a central strategic plan. Since January 2016, Yves Lévy has been the coordinator of the European HIV Vaccine Alliance (EHVA) consortium. He holds the positions of chair of the Immune-based Therapies Committee of the ANRS (French National Agency for Research on HIV and Viral Hepatitis), scientific director of the HIV Vaccine Program of the ANRS, member of the WHO Vaccine Advisory Committee, the Council of the Global HIV Vaccine Enterprise and other scientific and professional societies. Pr Lévy bas been appointed member of the UN Global Health Crises Task Force by Mr Ban Ki-moon (July 2016). He has also been appointed Dr Honoris Causa of the Imperial College of London (October 2016).

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Magnus Magnusson

Magnus Magnusson took up his duties as Director for Partnerships and Outreach in the Social and Human Sciences Sector at UNESCO on September 1, 2017. Prior to joining UNESCO, he held positions as Vice President for Emerging Markets and Sustainability at Eco Capacity Exchange; Head of Government Relations, Northern Europe at the Bill & Melinda Gates Foundation; Head of Business Development and External Relations at the United Nations Capital Development Fund; and Regional Manager at the Nordic Development Fund. He started his career at the Ministry for Foreign Affairs with desk responsibility for the World Bank, regional development banks, International Fund for Agricultural Development (IFAD- and microfinance. Thereafter he joined the Nordic Council of Ministers as Senior Advisor for the finance, transport and development cooperation sectors. He also acted as secretary to the Board of Governors of the Nordic Investment Bank, Nordic Development Fund and was a representative in the Board of the Nordic Project Fund. Subsequently he joined the United Nations Environment Programme/GRID-Arendal as Head of the Stockholm Office. A Swedish citizen, he has

an academic background in social sciences, business administration and economics, and environmental studies from Uppsala University, the Swedish Royal Institute of Technology, the Stockholm School of Economics and the University of California, Berkeley. He is a board member of the Stockholm Philanthropy Symposium Foundation and advisory board member of Hand in Hand USA, Global Vaccines Project and ECO Capacity Exchange.

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Jennifer Merchant

Jennifer Merchant obtained her PhD in political science from Sciences po Paris, and now teaches at Paris II University. Her research privileges a pluridisciplinary approach at the crossroads of political science, law, gender studies and bioethics in Anglo-American and European countries. She is currently working on two projects: analyzing from a comparative perspective (France/United States) policies relative to gender and health care and research, and comparative public policy analyses of the framing of human genome editing (HGE) and their impact on the future of human reproduction. She is a member of the Inserm Ethics Committee and of the Institut universitaire de France, and was a member of the U.S. National Academy of Sciences committee on HGE. Among her publications; *Procréation et politique aux États-Unis, 1965-2005* (Paris, Belin), “Les militants pro-life à l’échelle locale” (https://www.cairn.info/les-conservateurs-americains-se-mobilisent--9782746711457-page-142.htm), and “Assisted Reproductive Technology in the United States: Towards a National Regulatory Framework?” (https://www.cairn.info/revue-journal-international-de-bioethique-2009-4-page-55.htm).

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Peter Mills

Peter Mills is Assistant Director at the Nuffield Council on Bioethics, an independent body that examines and reports on ethical issues in biology and medicine. His work relates to a wide range of issues at the intersection of science, ethics and public policy, and has included major reports on emerging biotechnologies (December 2012), the linking and re-use of data in biomedical research and health care (February 2015) and genome editing (September 2016). He is currently leading two further projects on genome editing: in human reproduction and in livestock. He also sits on the Council of Europe Bioethics Committee as the UK delegate. From 2007 to 2010 he was Head of Human Genetics and Bioethics at the UK Department of Health. As well as heading the secretariat for the Human Genetics Commission, the UK Government's independent advisory body on the implications of developments in human genetics, he has also represented the UK government on a number of international bioethics bodies. Before moving to the Department of Health, he led a number of high-profile policy initiatives at the Human Fertilisation and Embryology Authority, concentrating on ethical, legal, and psychosocial aspects of developments in assisted conception and human embryo research.

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Francisco J.M. Mojica

Francisco Juan Martínez Mojica is Associate Professor of microbiology at the Department of Physiology, Genetics and Microbiology, University of Alicante (Spain). He graduated with a degree in biology from the University of Valencia (Spain, 1986). In 1993, he earned his PhD. in biology, for research on the response of halophilic microorganisms to stress factors (University of Alicante), under supervision by Dr. Francisco E. Rodríguez Valera and Dr. Guadalupe Juez Pérez. During the stage of elaboration of his thesis, he visited the laboratory of Dr. Patrick Forterre at the University Paris XI (Orsay, France, 1991-1992), where he began in the analysis of the DNA structure. He carried out postdoctoral research work on bacterial motility at the University of Utah (USA, 1993) with Dr. John S. Parkinson (University of Utah, Salt Lake City, USA, 1993) and on gene regulation and DNA topology at the lab led by Dr. Christopher F. Higgins at the University of Oxford (UK, 1995-1996). In 1997, he returned to the University of Alicante to hold a faculty position as Professor of microbiology.

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Luis Montoliu

Lluis Montoliu graduated with a degree in biological sciences (1986) and obtained his PhD in molecular genetics (1990) at the University of Barcelona. Currently, he is a Research Scientist of the Spanish National Research Council (CSIC) and established his laboratory at the National Centre for Biotechnology (CNB), in Madrid (Spain) in 1997, after two postdoctoral periods in Heidelberg (German Cancer. Since 2007 he was also appointed researcher at the Spanish Research Initiative on Rare Diseases where he is now serving at its steering committee. Since 1998, he is Honorary Professor at the Autonomous University of Madrid and, since 2007, Director of the Spanish node of the European Mouse Mutant Archive. Including his PhD, from 1986, where he worked in plant molecular genetics, in maize, he has been always working on the genetic modification of organisms. At the CNB he leads a research team interested in basic science, to understand the mechanisms controlling gene expression and organization in mammalian genomes, and in applied science, generating animal models for the study of human rare diseases, such as albinism. He has contributed significantly to animal transgenesis methods developing artificial chromosome transgenesis. He has also pioneered the use of gene-editing CRISPR approaches in Spain for the functional analysis, in vivo, of regulatory elements found in the non-coding genome. Currently, he is involved in collaborative efforts towards the universal genetic diagnosis of all known forms of albinism. He chairs the European Society for Pigment Cell Research and serves at the boards of additional societies. In 2006, he founded the International Society for Transgenic Technologies for which he has served as President since inception to 2014. He is a member of the CSIC Ethics Committee and the Ethics Panel of ERC in Brussels.

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Lauren Roberts

Lauren Roberts is the Director of Support at Genetic Alliance UK, an alliance of 200 patient organisations working to improve the lives of patients and families affected by all types of genetic conditions. Genetic Alliance UK aims to ensure that high-quality services, information and support are provided to all who need them and actively support research and innovation across the field of genetic medicine. Lauren Roberts has a MSc in anthropology and development and has spent most of her career working with families of disabled children. Since joining Genetic Alliance UK in 2011 her primary focus has been developing the SWAN UK (syndromes without a name) support network for families of children affected by undiagnosed genetic conditions. More recently she has also been overseeing Genetic Alliance UK's Building Rare Communities project, which seeks to enable families of children with rare conditions, often obtained via genomic sequencing, to develop their own support groups. She also takes a particular interest in developing and providing opportunities for patients, families and parent carers to have an active and informed voice in decisions that affect them.

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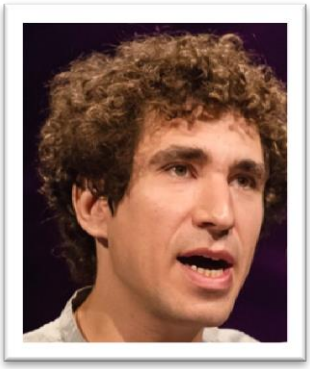
Paul-Loup Weil-Dubuc



Dr Paul-Loup Weil-Dubuc is a researcher in the field of ethics and political philosophy. He devoted his PhD thesis to the following question: how could social health inequalities could be justified? He is now working at the Espace éthique Île-de-France. His main topics of interest are: recognition and justice issues raised by cognitive impairment; ethical and political issues regarding predictive medicine. Paul-Loup Weil-Dubuc is also the chief editor of the *Revue française d'éthique appliquée*, an academic and francophone publication dealing with all the fields of applied ethics.

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Cyril Sarrauste de Menthière

Cyril Sarrauste de Menthière is responsible for the valorization, transfer of technology and scientific mediation of the Institute of Human Genetics (IGH, CNRS-University of Montpellier, France). Initially trained as a physicochemical engineer, he obtained a Ph.D. in biochemistry and chemistry from the University of Montpellier. As a CNRS Research Engineer, he was responsible for the bioinformatics and IT development for research support at the IGH. Because of his background and his various interests in particular in genetics and computer science, he joined the boards of directors of various (French) learned societies such as the French Genetics Society (SFG), the French Association of Cytogeneticists (ACLF), the Nîmes DNA Learning Center and the National Association of Medical Genetics Practitioners and Teachers (CNEPGM). He is also a member of the council of the Biological and Chemical Sciences of Health doctoral school. In recent months he has focused on the organization of international conferences on CRISPR-Cas9, and has given general public lectures (in French) on this same technology. He is involved in citizen conferences on bioethics. Currently he is setting up a project on artificial intelligence and gene regulation.

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FOSTERING RESPONSIBLE RESEARCH WITH GENOME-EDITING TECHNOLOGIES: a European Perspective

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The authors declare that they have no conflict of interest

Summary In this consensus paper resulting from a meeting that involved representatives from more than 20 European partners, we recommend the foundation of an expert group (European Steering Committee) to assess the potential benefits and draw-backs of genome editing (off-targets, mosaicisms, etc.), and to design risk matrices and scenarios for a responsible use of this promising technology. In addition, this European steering committee will contribute in promoting an open debate on societal aspects prior to a translation into national and international legislation.

Keywords:
CRISPR-Cas; gene editing; science and society; responsible research and innovation

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For several years, scientists have been trying to develop techniques to specifically target and modify sequences within complex genomes. New technologies that allow the specific addition, removal, or modification of DNA sequences are summarized under the term ‘genome editing’ (Gaj et al. 2013). If the genome edited sequence corresponds to a gene, then the amino-acid sequence of the protein encoded by the gene may be altered. In some cases, this may lead to changes in its activity and function, as well as its location or lifespan. Thereby, genome editing may result in the correction of a defective function of a gene within a specific biological context. The latest advance in genome editing by CRISPR (clustered regularly interspaced short palindromic repeats)/Cas (Mojica and Montoliu 2016), is unquestionably a major technological revolution. This is illustrated by the rapid expansion of the scientific literature on CRISPR/Cas9-mediated genome editing. More than 3,000 peer-reviewed articles citing “CRISPR or Cas9” had been published by January 2017 (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5064173/). There is also a continuing emergence of novel related tools which are potentially more efficient than CRISPR-Cas9 (Barrangouv and Doudna 2016) such as Cas12a (Cpf1) (Zetsche et al. 2015). The economic potential of gene editing seems enormous and major companies are investing millions of euros in CRISPR-Cas9. In parallel, large numbers of patents have been filed and there are ongoing disputes over patents and licensing rights (http://www.nature.com/news/titanic-clash-over-crispr-patents-turns-ugly-1.20631), the outcomes of which could be worth billions of euros.

CRISPR-Cas9 is a genome editing tool that is able to induce a double-strand break into DNA at selected sites in the genome of any cell and specy. In practice, a guide RNA (gRNA) leads the DNA endonuclease Cas9 to a specific sequence to instruct a cut through the DNA strands (Braff et al. 2017). The gRNA must be homologous (complementary) to the desired target sequence and then Cas9 binds to the chosen genomic locus close to a short DNA sequence motif called PAM (protospacer adjacent motif). The Cas9 enzyme cuts through the DNA creating a double-strand break. The cell may then use different mechanisms to repair the break. These include DNA repair systems present in all cells and result in non-homologous end joining (NHEJ), or by homology-directed repair (HDR). As a result, sequence modifications are introduced at the break site (insertion, deletion or mutation). If the objective is to knock-down the expression of the targeted gene, it is sufficient to allow the NHEJ repair system to mend the break by inserting and/or deleting

(INDELs) nucleotides randomly. As the repair is error-prone, the “repaired gene" will most likely be mutated. If the objective is to correct a pre-existing mutation, then the repair must restore the original sequence after the break of the mutated gene. For this to happen, the introduction of a template DNA sequence is necessary and the cell repairs the break by copying the template sequence. The same applies to introducing a mutation that mimics a variant of a gene. It is also possible to simultaneously modify multiple targets. Of note, the repairing mechanisms will usually trigger the generation of multiple and diverse edited alleles, and hence normally lead to mosaicism in cells or animals. Interestingly, it was recently shown that a bacteriophage protein can switch-off the CRISPR/Cas9 activity, which should permit a certain level of control of CRISPR/Cas9-mediated gene editing, although this approach does not revert a modification already initiated (Rauch et al. 2017).

The simplicity of carrying out this procedure enabled the pioneers of genome editing technology, such as George Church from Harvard, to declare that the technique could "on a simple whim allow anyone to do almost everything”. Furthermore, the Church team described orthologs of Cas9 with improved selectivity, specificity and efficiency of targeting a particular DNA sequence (Braff et al. 2017). Beyond coding and non-coding DNA, targeted modifications of the epigenome at specific sites, particularly for therapeutic purposes, are now feasible.

Almost all areas of biological research are, or will soon be penetrated by the rapid emergence and development of genome editing technologies. With respect to humans, genetic changes of somatic cells, germ cells or embryos are clear targets for these new approaches. However, most of the therapeutic strategies are expected to be developed for somatic (or ex vivo) gene-therapy approaches, not involving embryos (http://www.nature.com/news/crispr-gene-editing-tested-in-a-person-for-the-first-time-1.20988). As regards non-human animals, both livestock and laboratory animals are candidates for these new methodological approaches. Environment and biodiversity are also clearly among the potentially affected areas. Gene drive approaches (Gantz and Bier 2015) could be applied for pest control where a CRISPR-Cas9 cassette is able to self-perpetuate, thereby rapidly spreading any genetic information among all individuals of a population. This possibility also raises concerns about potential misuse and that gene editing technologies may be used for the development of genetic weapons of mass destruction (https://www.dni.gov/files/documents/SASC_Unclassified_2016_ATA_SFR_FINAL.pdf). Therefore, together, these new possibilities lead us to consider the use of CRISPR-Cas9 technology in the light of the regulation that currently frames and oversees contemporary genomic technologies, and how they might incline us to reconsider these regulations. The same questions are raised by related genome editing tools with similar possibilities, including engineered meganucleases, zinc finger nucleases (ZFN) and transcription activator-like effector nucleases (TALEN).

Several academic institutions such as the US NAS/NAM (http://nationalacademies.org/gene-editing/consensus-study/meetings/index.htm#slides3) and, more recently, the European Academies Science Advisory Council (EASAC) (https://www.knaw.nl/shared/resources/internationaal/bestanden/easac-report-31) addressed the ethical, legal and social aspects (ELSA) raised by these new genome editing

tools. Based on its report published December 2015, the INSERM Ethics Committee organised a meeting in Paris on March 16th, 2016, with a wide range of European stakeholders and experts to reflect on, and foster, responsible research with CRISPR-Cas (http://www.inserm.fr/inserm/accueil/qu-est-ce-que-l-inserm/l-ethique-a-l-inserm/seminaires-du-comite-d-ethique/atelier-du-comite-d-ethique-inserm-fostering-responsible-research-with-crispr-cas9/(language)/eng-GB). Consensus recommendations are captured in the following position outlined below. Obviously, due to the rapid scientific advances in this field, these principles will most likely require further modification in the future.

As the situation currently stands, no international consensus exists, similar to the one that resulted from the 'Asilomar Conference on Recombinant DNA' in 1975, although a recent proposal did debate the possibility of calling for an international ban on the gene-drive approach (Callaway 2016). We consider that a moratorium is not appropriate to promote good basic research practice and adequate safeguards. Of note, the new genome editing techniques do not raise fundamental new biological risks that have not already been encountered by existing technologies. However, since performing genome editing by the new tools is much easier, cheaper and faster than with the previously available technologies; these new applications must be thoroughly assessed.

Since basic research in the area should be permitted to continue, we propose that the following general principles should be adopted:

1- **To foster research that will assess the feasibility, the efficacy and the safety of genome editing techniques**, such as the benefit-to-harm balance of any potential clinical application can be evaluated. It is necessary to evaluate the efficacy of genome editing techniques, to estimate the impact of mosaicism at the on-target location, potential off-targets and of other adverse effects and to assess their clinical relevance. This task is essential in order to define what therapeutic approaches should be considered for use in humans, and which research institutions would then promote for these studies to be conducted according to standardized methods.

⟹ This aim could be addressed by establishing a European Steering Committee (ESC) gathering experts from a broad spectrum of relevant disciplines as diverse as molecular and cell biology, ecology, safety and a variety of social sciences, to evaluate:

- acceptable levels and types of off-target effects,
- acceptable levels of mosaicism,
- acceptable levels of epigenetic effects.

The ESC should rely on an open and transparent discussion process which should include various stakeholders, for example patient organizations, representatives of Ethics committees and of the economic sector, as well as representatives of the communication sector.

2- **To evaluate the potential adverse effects of gene drive applications** with a thorough risk assessment analysis and mitigated before environmental trials are undertaken outside the laboratory. These field exercises should be conducted using strict confinement

precautions similar to those that have already been developed for infectious and GMO´s approaches. Given the transmissible nature of gene drive genetic elements, as well as the irreversibility of genetic errors that may occur, assessments will have to be made over a long time period. Research on plausible risks should be developed. Measures will have to be foreseen in the event of unexpected adverse effects.

⟹ With a well thought-out procedure for the assessment of a benefit-to-harm balance in the long-term, the proposed European Steering Committee will produce risk analysis matrices, devise realistic scenarios and will produce recommendations for reversibility strategies in the case of adverse effects harmful for humans or for biodiversity.

3- **To reassess the ban on all modifications of the germ line nuclear genome for clinical application in human reproduction**. Many European countries have ratified the Oviedo Convention of the Council of Europe (http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/164), including its article 13 that is relevant to germ line genome editing. An open discussion is needed on a case-by-case analysis for a restricted number of genetic disorders, such as Huntington's disease that may be prevented by genome editing, as well as other very rare diseases for which we have no therapy. At the present time, there must be opposition to any demands for the modification of the related legal framework, in so far as clinical applications are concerned, until uncertainty about potential harms has been evaluated on the basis of research, and until consensus has been reached with multiple partners throughout civil society. Again, it is important that society maintains a broad confidence in science. This requires an appropriate oversight of laboratory work and of any medical and ecological application of genome editing techniques especially if it irreversible and permanent.

⟹ European research institutions and political decision-makers should cooperate in the definition of ethical standards and guidelines which determine what kinds of translational research and application of genome editing are admissible and are not.

4- **To be pro-active to prevent this technology from being hijacked by those with extremist views and to avoid misleading public expectation with overinflated promises.** Unlike many other new technologies applied to genetics, the new genome editing approaches indeed offer almost unlimited possibilities. Therefore, the scientific community must act with responsible openness and transparency. A major issue is to distinguish between the questions and concerns raised by the application of genome editing technologies in research, and their clinical application in patients. The role of legal measures is of considerable importance in this discussion in order to build a consensus given the high scientific uncertainty, the potential misuses and security risks, the ethical tensions, the conflicting interests and the rapid developments in this scientific area.

⟹ European research institutions should contribute to national and international initiatives addressing questions of freedom of research and of medical ethics. Participation in such international initiatives by experts from developing countries should be promoted and facilitated, since all countries worldwide are concerned and potentially be affected. International biorisk management as an inclusive approach to safety and security should be

expanded to cover the unique risks related to safety and security in the context of genome editing.

5- **To raise awareness about the distinction between the care/treatment of human diseases and human enhancement**. Certain therapeutic promises might engender dystopian expectations. As such, animated discussion about controversial technological advances in the life sciences is a very effective means of heightening public interest in research and embeds science at the heart of public culture. We must indeed foster increased debate within the scientific community and with the rest of civil society aiming at contributing to the advancement of a necessary global responsible scientific research and innovation.

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Final note
The present authors have accepted to be part of the proposed European Steering Committee. The INSERM Ethics Committee has taken in charge the preliminary support to establish the ESC. The temporary office is settled in Paris with FH and SF in charge. Beyond this European initiative and after the international meetings co-organized by INSERM Ethics committee and the Wellcome Trust in Buenos-Aires (30/10/2016) and Delhi (27-28/05/2017) which raised interest of Latin American and Indian representatives, we expect the ESC to join within an international steering committee dedicated to the same topics.

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FOSTERING RESPONSIBLE RESEARCH WITH GENOME EDITING TECHNOLOGY:

The Need for a Permanent Forum. The Main Goals for ARRIGE

Recent advances in editing the genome, particularly using CRISPR-Cas9, is unquestionably a technological "revolution" as demonstrated by the rapid expansion of the scientific literature and the continuing emergence of applications and innovative methods, including some potentially safer than CRISPR-Cas9, such as methods editing the RNA or the genome without cutting it.

Considering the huge potential impact on multiple aspects of our societies, from human health to the environment, and the high economic stakes, several Academies and institutional Ethics Committees have already tried to anticipate and address the ethical, legal and social implications (ELSI: the NIH speaks of ELSI https://www.genome.gov/10001618/the-elsi-research-program/) raised by these new technologies. Interestingly, numerous convergences already can be found in the many reports and recommendations published during the last 3 years on the subject, but no process has yet been set up to clarify how to translate these convergences into actions, and to maintain the continuous analysis of ELSI issues along with new scientific advances and technical applications. All the reports appear to agree on the need to engage all the stakeholders including the general public, but most remains to be done in this area. Therefore, experts in these techniques have a responsibility to the Society in order to devise a regulatory framework and promote the responsible use of genome-editing (GE) technologies.

The present proposal results from several converging initiatives. First, we refer to the reunion of a group of European stakeholders that originally met in Paris in March 2016, wrote some guidelines (including advocating a European Steering Committee) and began a series of joint meetings with African, Latino-American and Indian colleagues. Among shared conclusions were the need to think more ahead when enacting new legislation. It is crucial that we anticipate the next directives these issues are likely to engender rather than react every time, with years of delay, once a technology is out there, already widely used and raising unregulated issues. We should foster a governance risk-management approach, taking into account the many uncertainties. We also converged on the need for inclusive debate on “acceptability and desirability” extending to the civil society and not only limited to safety issues, potential health risks and health benefits. We need transparency to expose what science is doing, what science could do and what science should not do. But we also know that science is not the whole picture and we will have to deal with the race towards the market of some applications, the constraints of some patent fights or the development of the “Do It Yourself” movement.

The aforementioned European initiative is only one among many. We obviously recognize and value the reports produced by high-profile colleagues such as the US National Academy of Sciences or European Academies (EASAC). We are also aware of the efforts and requests expressed by patient associations such as EURORDIS. Some of us

also participated in OECD initiatives on gathering regulators of genome editing for advanced therapies.

It is now time to join our efforts to team up and to consider these needs, to call for the building of an international association gathering scientists, research institutions and sponsors, regulators, representatives of the economic sectors potentially impacted by new genome-editing tools (health, agriculture, environment, etc.), media, and the general public including patient associations and NGOs.

The goals of this association, which we propose to name Association for Responsible Research and Innovation in Genome Editing (ARRIGE), should be to promote a global governance of GE. To do so we first need to ask “What should we steer?”, meaning to define the field of questions that need to be tackled; “How can we steer?”, in other words to define realistic goals to actually assist the process of governance. As an example with safety and security, to provide researchers with framework and guidance in assessing. And finally “Whom should we steer?”, and it should be both the agencies and the public alike. People participating in ARRIGE should provide guidance with the proposal of a toolbox containing specific questions to be addressed. Such a toolbox will be of interest for researchers and regulators, but also for public engagement initiatives and could become a strong reference. ARRIGE should be the place where, on the basis of an open field, open science and open discussion, debates would take place on the basis of what has already been done. As an international association ARRIGE membership should be grounded in the voluntary choice to do so and the engagement and investment of its partners to achieve our goals.

After a one-day meeting in Paris on November 13, 2017, a mailing list was launched (crispr.esc@cnb.csic.es) which rapidly gained over 100 subscriptions of persons world-wide who are interested in our proposal. A web page containing this initial document, our White Paper, the presentations used in our last meeting in Paris and most reports and statements available on the subject can also be found there:
http://wwwuser.cnb.csic.es/~montoliu/CRISPR/ethics/.

This now leads us to this kick-off meeting to set up the structure of **ARRIGE**.

This new association will exist only if you join and bring your expertise, your commitment and expectations about the responsible use of GE.

Consequently, now: as individual or as representative of your institution, join us to contribute by sending a mail to:
join@arrige.org

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INSERM ETHICS COMMITTEE

By trying to forge a relationship between the scientific world and society, the Inserm Ethics Committee promotes ethical awareness among Inserm staff on ethical issues raised by scientific medical research and health research.

Reflections led during the monthly plenary meetings are then aimed at anticipating and addressing new ethical challenges linked to the evolution of research in life sciences. The committee contributes to the organization of debates in emerging areas of biomedical innovation, members organize workshops reflection, write position papers, and reports. The committe summarizes this work during the annual Inserm Ethics Committee Day, were it is presented to the Inserm researchers and to general public. The committee is an open institution, which interacts with other public research bodies concerned with ethical issues.

The Inserm Ethics Committee is composed of 15 members appointed every 3 years.

Members are divided into 5 working groups addressing current societal issues:

- Human embryo & development
- Research with direct access to patients
- Gender & health research
- Perception of relationship with lab animals by the researcher
- Ethics and health research in less developed countries
- Ethics of innovation

Website: https://www.inserm.fr/en/research-inserm/ethics/inserm-ethics-committee-cei/inserm-ethics-committee-cei

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Website: https://cvt.aviesan.fr/cvt-aviesan/

RÉGION ÎLE-DE-FRANCE

Enjoying a leading economic position in Europe with more than 500,000 firms, 500 company headquarters, and 150,000 researchers, Paris Region, also called in France "Région Île-de-France", ranks among the most competitive regions for research and development, innovation, and entrepreneurship.
This exceptional R&D potential goes hand in hand with a remarkable higher education system, praised for its quality and opening. Seventeen universities among the most prestigious in the world, like the Sorbonne, along with more than 300 engineering, health, management, architecture, and art schools in Île-de-France offer a internationally renowned education, providing each and every one with the best adapted training curriculum. With one student out of four being trained in Paris Region, university life also benefits from a rich and effusive offer in terms of culture and entertainment.
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Website: http://parisregion.eu/discover.html/

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Espace éthique Île-de-France (ERER/IDF) is a public organisation headed by Pr. Emmanuel Hirsch and devoted to training health practitioners, creating networks and research in the fields of health care and biomedical ethics across the region of Île-de-France. Research activities of ERER/IDF are linked with the Department of Ethics of the Paris-Sud/Paris-Saclay University and the laboratory of excellence Distalz dedicated to the comprehension of Alzheimer's disease. ERER/IDF is also associated with a national organization devoted to ethical reflections regarding neurodegenerative diseases (with the implementation of the Neurodegenerative Diseases Plan 2014-2019).

Website: http://www.espace-ethique.org/

GENOPOLE

As the first French bio park dedicated to genetic research and applied biotechnology in the health and environmental areas, Genopole clusters 19 research entities, 86 biotech companies as well as university groups (University of Évry - Val-d'Essonne). Its goal – to foster and develop research in genomics, post-genomics and associated sciences, technology transfer to the industrial sector and high-level instruction in those fields, as well as to create and support biotech firms. Genopole is supported by the French government, the Île-de-France Regional Council, the Essonne County Council, the Grand Paris-Sud Metropolitan Area, the town of Évry and the AFM-Téléthon (www.genopole.fr).

Website: https://www.genopole.fr/?lang=en#.Wqpvf3zA_3g