

## ARRIGE 2020 MEETING

Association for Responsible  
Research and Innovation In Genome Editing

SATURDAY NOVEMBER 14th, 2020  
ON-LINE



The Association for Responsible Research and Innovation in Genome Editing (ARRIGE) aims at providing a comprehensive setting for all stakeholders (academics, private companies, patient organizations, citizens and decision makers) to allow the development of the genome editing technologies in a safe and socially acceptable environment. ARRIGE 2020 Meeting will be the occasion for a variety of stakeholders to present their works, considerations or points of view on the use of genome editing technology in light of recent research and burning issues on the international scene and for ARRIGE to share its annual review and objectives.

<https://arrige.org>

### **Board:**

Lluís Montoliu, Hervé Chneiweiss, François Hirsch, Christine Lemaitre, Cyril Sarrauste de Menthière, Jennifer Merchant, Marion Abecassis.

### **Scientific Committee:**

Chair: Gaétan Burgio (Australia), Vice-Chair: Tony Nolan (UK)  
Janet Rossant (Canada), Matthew Porteus (USA), Stephen Ekker (USA), Lydia Teboul (UK), Bruce Whitelaw (UK), Yann Herault (France), Jerome Amir Singh (Canada), Eleonore Pauwels (USA), Ayola Akim Adegniko (Gabon), Fabiana Arzuaga (Argentina), Mylène Botbol (Belgium), Pierre Jouannet (France), Amar Jesani (India), Josep Casacuberta (Spain), Martina Crispo (Uruguay), Juraj Koppel (Slovakia) and Bernard Baertschi (Switzerland)

## SUMMARY

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PRESENTATION OF SPEAKERS AND ARRIGE BOARD MEMBERS..... **6**

# PROGRAM

## ON-LINE MEETING

<b>GENERAL ASSEMBLY (only for ARRIGE Members)</b>		
2:00 – 3:00	<b>ARRIGE General Assembly</b>	<b>ARRIGE Board Chaired by Lluís Montoliu</b>
<b>SESSION 1 - Keynote Lecture on the Latest Genome Editing Techniques</b>		
Chair: <b>Lluís Montoliu</b> (ARRIGE)		
3:00 – 3:30	<b>CRISPR 2020: latest advances and applications</b>	<b>Martina Crispo</b> (Pasteur Institute – Uruguay)
<b>SESSION 2 - Public Engagement &amp; Genome Editing; SC Report</b>		
Chair: <b>Virginie Bros-Facer</b> (Eurordis)		
	<b>Patients' views on genome editing</b>	<b>Nick Meade</b> (Genetic Alliance – U.K.)
3:30 – 4:00	<b>ARRIGE's SC Report on Gene Drive</b>	<b>Gaetan Burgio</b> (Australian National University; ARRIGE SC – Australia)
	<b>10-minute Q/A</b>	
<b>BREAK</b>		
<b>SESSION 3 - Latest News on Genome Editing in Animals and Plants</b>		
Chair : <b>François Hirsch</b> (ARRIGE)		
	<b>The promise of CRISPR and gene drive systems to end malaria in Africa</b>	<b>Elena Gómez-Díaz</b> (CSIC – Spain)
4:30 – 5:10	<b>EU-COST Action PlantEd and recent developments in gene editing for agriculture</b>	<b>Ruud de Maagd</b> (Wageningen University – Netherlands)
	<b>10-minute Q/A</b>	
<b>SESSION 4 - Latest News on Genome Editing in Human and Governance</b>		
Chair : <b>Hervé Chneiweiss</b> (ARRIGE)		
	<b>Reflections on Emerging Developments</b>	<b>Eric Meslin</b> (Council of Canadian Academies – Canada)
5:10 – 5:50	<b>Governance of Human Genome Editing</b>	<b>Alta Charo</b> (University of Wisconsin, member of U.S. NAS – U.S.)
	<b>10-minute Q/A</b>	
<b>CONCLUSION</b>		
5:50 – 6:00	<b>Wrapping up and conclusions</b>	<b>Jennifer Merchant</b> (ARRIGE) & <b>Marion Abecassis</b> (ARRIGE)

## **PRESENTATION OF SPEAKERS, CHAIRS AND ARRIGE BOARD MEMBERS**

Marion **ABECASSIS**

Virginie **BROS-FACER**

Gaetan **BURGIO**

Alta **CHARO**

Martina **CRISPO**

Hervé **CHNEIWEISS**

Ruud **DE MAAGD**

Elena **GOMEZ-DIAZ**

François **HIRSCH**

Christine **LEMAITRE**

Nick **MEADE**

Jennifer **MERCHANT**

Eric **MESLIN**

Lluis **MONTOLIU**

Cyril **SARRAUSTE DE MENTHIÈRE**

## Marion ABECASSIS



Marion Abecassis is an attorney-at-law admitted to practice in Paris and New York, focusing her practice in life sciences and actively involved in the field of bioethics. She assists French and international health care stakeholders at the Paris office of McDermott, Will & Emery AARPI (contracts, regulatory, pre-litigation) and she is the associate in charge of Pro Bono. In parallel, she is a permanent guest of the Inserm Ethics Committee since April 2016 (with a particular focus on research on embryos and use of genome-editing techniques) and is a member of the Board of ARRIGE since its creation. She is a member of the *Conseil d'Administration* of Konexio (association promoting the inclusion of refugees and disadvantaged populations through tech skills training and community building). Publications: co-author of "Fostering responsible research with genome editing technologies: a European perspective" *Transgenic Research* 2017 (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5601998/>); author of *Artificial Wombs: "the Third Era of Human Reproduction"* and *the Likely Impact on French and U.S. Law*, *Hastings Women's Law Journal*, Jan 2016.

She is a member of the Paris and the New York Bars. She holds a Master in health law from Université Paris-Descartes (France) and a Master in global health law from Georgetown University (United States) under a Fulbright Grant as well as a Lurcy and a Monahan Grants.

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## Virginie BROS-FACER



Virginie joined EURORDIS in 2015 as Research Infrastructure Project Manager, later becoming Scientific Director. Her responsibilities include managing all EURORDIS activities related to infrastructures and technologies facilitating rare disease research such as patient registries, biobanks, clinical bioinformatics and scientific innovation (including genomics and next generation sequencing) as well as ethical issues surrounding this pre-clinical research.

Prior to joining EURORDIS, Virginie worked for several research funding organisations in the UK, including as Director of Medical Research for Sparks, a children's medical research charity based

in London.

Virginie holds an MSc and a PhD in Neuroscience from King's College London and also worked at the UCL Institute of Neurology on several research projects aiming to develop new therapeutic strategies for motor neuron disease and other neuromuscular disorders.

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## Gaetan BURGIO



Dr. Gaetan Burgio, is a geneticist Group leader at The John Curtin School of Medical Research (JCSMR) at the Australian National University (ANU). Gaetan was born in France and completed his education at Paris. He graduated in 2002 with a Medical Doctor Degree and completed his PhD in 2008 from Pasteur Institute at Paris. He migrated to Australia as a postdoctoral researcher at the University of Tasmania from 2008 to 2012 and Macquarie University at Sydney from 2012 to 2015. In 2015 he was appointed as a group leader at JCSMR to establish his research program on the development CRISPR/Cas9 gene editing technology. His current research aims to explore the diversity of the bacterial defence systems against the phage with an emphasis on CRISPR systems. He also leads a mouse transgenesis facility, which generates CRISPR edited mice and cell lines to the research community in Australia and overseas. He is member of the scientific committee of ARRIGE.

**Presentation:** ARRIGE Scientific Committee Report on Gene Drive.

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## Alta CHARO



Alta Charo, J.D. is the Warren P. Knowles Professor of Law & Bioethics at the University of Wisconsin. She is a member of the U.S. National Academy of Medicine, and co-chaired its committees on stem cell research and genome editing. She was a member of Pres. Clinton's National Bioethics Advisory Commission, and in government worked as a policy analyst at the congressional Office of Technology Assessment, the US Agency for International Development, and the FDA. She now serves on the WHO advisory committee on global governance of genome editing, as well as the U.S. National Academies of Medicine and of Science standing committees on emerging infectious disease threats and on emerging science technology

issues.

**Presentation: Governance of Human Genome Editing.**

**Contact: [alta.charo@wisc.edu](mailto:alta.charo@wisc.edu)**

## Martina CRISPO



Martina leads a research team focused in the production of in vivo and in vitro embryos in several species. Her main expertise is embryo micromanipulation and production of genetically modified animals, generating and applying that knowledge in experimental animals and productive species. Under her direction the first transgenic animals by pronuclear microinjection, homologous recombination in embryonic stem cells, transposons (SBT), lentivirus technologies and CRISPR were born in Uruguay. She coordinated the production of the first transgenic lambs born in Latin America. She works with CRISPR/Cas9 system since 2014 with successful results, generating several mouse models and the first reports of genetically edited sheep in the world, with novel developments in productive species recently published (2020). She has been in the Board of Directors of the International Society for Transgenic Technologies until October 2020 (2014-2020), and she is member of the scientific committee of ARRIGE.

**Presentation: CRISPR 2020: latest advances and applications.**

**Contact: [crispo@pasteur.edu.uy](mailto:crispo@pasteur.edu.uy)**

## 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 the adviser for life sciences and bioethics to the French Minister for Research and Technology (April 2000 to April 2002) and presently President of the International Bioethics Committee of UNESCO (IBC), vice-president of ARRIGE, head of the Inserm Ethics Committee and member of the French National Consultative Ethics Committee (CCNE, 2013-2017). He was also chief editor of *Médecine/Sciences* (2006-2016).

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## Ruud DE MAAGD



Ruud obtained his MSc degree in Biology at the University of Utrecht (Netherlands) in 1984. He obtained a PhD in Biology at the Dept. of Plant Molecular Biology, University of Leiden in 1989 and continued in a postdoc position there until 1991. From 1991 to 1992 he had a Postdoc position (with a Dutch NWO fellowship) in the group of Prof. Chris Lamb at the Plant Biology Laboratory of the Salk Institute of Biological Studies, in San Diego, USA. From 1993 to 1999 he worked as Junior Scientist and from 1999 to 2004 as Senior Scientist and project leader in the Cluster Biocides, Business Unit Bioscience, of Plant Research International, Wageningen (formerly CPRO-DLO). He was project leader of several projects dealing with structure/function-studies on *Bacillus thuringiensis* delta-endotoxins, improved Bt-toxin hybrids, expression of Bt toxins in plants and biological safety of insect-resistant transgenic plants. From 2004 to the present he was Senior Scientist/Project leader in the



cluster Plant Development Systems, Business Unit Bioscience of Wageningen Plant Research (formerly Plant Research International and CPRO-DLO). Project leader of several projects dealing with fruit (particularly tomato) development and ripening, and the role of transcription factors and cell cycle proteins therein. In the past 5-6 years he has been using and working on optimization of CRISPR/Cas mutagenesis in plants. He has coordinated two international EU framework projects and was participant in several others. Currently he is WG1 vice-chair in EU-COST action CA18111 -PlantEd- "Genome editing in plants - a technology with transformative potential".

**Presentation:** EU-COST Action PlantEd and recent developments in gene editing for agriculture.

**Webpage:** <https://www.wur.nl/en/Persons/Ruud-dr.-RA-Ruud-de-Maagd.htm>

## Elena GOMEZ-DIAZ



Elena Gómez-Díaz is an Evolutionary Parasitologist at the Institute of Parasitology and Biomedicine López-Neyra of the Spanish National Research Council (CSIC) in Granada (Spain). Her lab has two main areas of research applied to a major human health problem which is malaria: the study of the epigenomics of the malaria-causing parasite *Plasmodium*, and its mosquito vector. Ongoing efforts are underway in the team to build high quality reference genomes from parasite field-isolates and use these resources to gain a deep understanding of how the parasite regulates its genome during development, and to adapt quickly in the context of the changing environment of the host. For this purpose we combine state of the art single-cell analyses and CRISPR-Cas9 gene editing approaches, focusing on the most important part of the parasite life cycle: "the mosquito". The use of the biological model of the mosquito and natural parasites isolates, allow us to study gene regulation "in vivo" and in conditions that mimic the natural context of the disease. The other research area focuses on a comprehensive characterisation of the regulatory genome of *Anopheles gambiae*, as well as the dynamic changes that occur in mosquito' gene regulatory networks during an infection. The ultimate goal is gaining an epigenomic and evolutionary perspective on these organisms, with the aim to contribute to blocking their adaptation potential and design more effective strategies to end malaria.

**Presentation:** The promise of CRISPR and gene drive systems to end malaria in Africa.

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## François HIRSCH



François Hirsch graduated in immunology from the Pasteur Institute and in Science & Medical Ethics from Paris-Sud University. He spent 30 years at the National Institute for Health and Medical Research (Inserm) holding various positions in scientific research and research administration, including Secretary General of the ethics committee and deputy director of the Health Technologies Institute. For three years, he was a national expert seconded to the Governance and Ethics Unit of the European Commission (EC), where he contributed to the organization of the ethical evaluation of the research projects submitted for funding. François Hirsch is currently a member of the Inserm Ethics Committee, in charge of

one of its working groups "Health Research in the South"; Secretary General of the Ile-de-France 7 Committee for the Protection of Persons (CPP, national registered IRB) and a member of the Board of Directors of the National Conference of CPPs. At the international level, in addition to his responsibilities as Secretary General of the International Association for Responsible Research In Genome Editing (ARRIGE) of which he is one of the founders, he is an evaluator for various EC agencies, including the EDCTP platform (a tool for financing biomedical research in sub-Saharan Africa), a member of the European network of research ethics committees (EURECNet) and an ethics expert for the European network of veterinary medicine to combat zoonoses and antibiotic resistance. He also participated in the WHO reflection group on the ethical approach to vector-borne diseases in Southern countries.

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## Christine LEMAITRE



Christine Lemaître has been working as engineer at Inserm (the French National Institute of Health and Medical Research) since 2007. In 2009, she joined the Multi-organization thematic institutes "Cell biology, development and evolution" and "Genetics, genomics and bioinformatics", as scientific policy officer. These institutes, parts of the French National Alliance for Life Sciences and Health (Aviesan), seek to take stock of the research situation in these fields, put forward specific actions for improving the performances and competitiveness of French research and provide effective coordination between all the organizations

and institutions concerned by these themes. Christine Lemaitre is acting in the Inserm ethics committee since March 2018.

Christine Lemaitre is graduated of the National High School of Engineering in Agronomy and Food Industries, of Nancy.

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## Nick MEADE



Nick Meade is Director of Policy at Genetic Alliance UK, the national charity working to improve the lives of patients and families affected by genetic, rare and undiagnosed conditions. Genetic Alliance UK is an alliance of over 200 patient organisations. He leads work which focuses on the commissioning of healthcare services and access to therapies, on genetic testing and genomic technologies, and on reproductive choice. He represents patients on panels and committees in the UK and Europe, including Eurordis, NICE and NHS England. Genetic Alliance UK collaborated with the Progress Educational Trust on the project 'Basic Understanding of Genome Editing', addressing the need for understanding

and clear vocabulary in this area.

**Presentation:** Patients' views on genome editing.

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## Jennifer MERCHANT



Jennifer Merchant obtained her PhD in political sciences from *Sciences po* Paris, and now teaches at the *Université de Paris II*. 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: 1° analyzing from a comparative perspective (France/United States) policies relative to gender and health care and research, and 2° 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 Human Genome Editing. Among her

publications; *Procréation et politique aux Etats-Unis, 1965-2005* (Paris, Belin 2006), “Assisted Reproductive Technology in the United States: Towards a National Regulatory Framework”, *IJB* 2009 (<https://www.cairn.info/revue-journal-international-de-bioethique-2009-4-page-55.htm>), *Access to Assisted Reproductive Technologies: The Case of France and Belgium* (dir.), Berghahn October 2020 (<https://www.berghahnbooks.com/title/MerchantAccess>), and “Is Our Personal Genetic Data Really Protected; A Panorama France/ United States”, *Assas International Law Review*, n° 2, 2019, p. 129-158: [https://www.u-paris2.fr/sites/default/files/document/cv\\_publications/rdia\\_n2\\_-\\_2019.pdf](https://www.u-paris2.fr/sites/default/files/document/cv_publications/rdia_n2_-_2019.pdf).

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## Eric MESLIN



Eric Meslin is currently the President and CEO of the Council of Canadian Academies (CCA) a not-for-profit organization founded by Canada’s three leading learned societies - the Royal Society of Canada, Canadian Academy of Health Sciences, Canadian Academy Engineering which conducts independent, evidence-based expert assessments of leading policy topics for the Government of Canada. Prior to CCA, Meslin spent 15 years at Indiana University where he was Founding Director of the Indiana University Center for Bioethics, Associate Dean for Bioethics in the IU School of Medicine, and a tenured Professor of Medicine, of Medical & Molecular Genetics, and of Philosophy. Trained as a

philosopher and bioethicist Meslin has held academic positions at the University of Western Australia and Université de Toulouse. He is currently Adjunct Professor, Dalla Lana School of Public Health University of Toronto, Senior Fellow of the PHG Foundation at University of Cambridge, Visiting Fellow Centre of Genomics and Policy at McGill University, and as 2020-2023 Mentor for the Pierre Elliott Trudeau Foundation. He has had an equally productive administrative and policy career. He was Bioethics Research Director of the Ethical, Legal, and Social Implications (ELSI) program at the National Human Genome Research Institute in the early years of the Human Genome Project, and then Executive Director of the U.S. National Bioethics Advisory Commission established by President Bill Clinton which provided advice to the White House and the US Congress on stem cell science, cloning, international clinical trials, genomics, and related topics.

Among his honors Dr. Meslin is an elected Fellow of the Canadian Academy of Health Sciences and The Hastings Center, and in 2007 was appointed a Chevalier de l’Ordre Nationale du Mérite.

**Presentation:** Reflections on Emerging Developments.

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**Lluís MONTOLIU**

Lluís Montoliu President of ARRIGE, is a CSIC Scientist and also researcher at the Spanish Research Initiative on Rare Diseases at the National Centre for Biotechnology in Madrid, Spain. He has been Honorary Professor at the UAM for 20 years (1998-2018), and, since 2007, is the Director of the Spanish node of the European Mouse Mutant Archive (EMMA/INFRAFRONTIER).

Including his PhD studies, from 1986, where he worked in maize molecular genetics, he has been always working with genetically modified organisms (GMOs). Since 1991, he has been working in several scientific projects within the field of animal transgenesis. At the CNB, since 1997, he leads a research team interested in basic science, to understand the mechanisms controlling gene expression and

organization in mammalian genomes, and in applied biomedical 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 genome-editing CRISPR approaches in Spain for the functional analysis, in vivo, of regulatory elements found in the non-coding genome. He has published more than 120 scientific articles and co-invented 6 patents in the field.

He is the current President of the European Society for Pigment Cell Research (ESPCR) and serves at the boards of additional national and international societies. In 2006, he founded the International Society for Transgenic Technologies (ISTT) for which he served as President until 2014. He is the President of the CSIC Ethics Committee and a member of the Ethics Panel of ERC in Brussels. Besides research, he is also interested in bioethics, education and popular science and has published several books on albinism and CRISPR tools. He has received several awards for his research and popular science activities.

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**Cyril SARRAUSTE DE MENTHIERE**

Cyril Sarrauste de Menthière, treasurer of ARRIGE, 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 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, Montpellier University (ED CBS2). In 2017-2018 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 also involved in citizen conferences on bioethics. For these last 2 years he is member of the scientific council of the French Society of Predictive and Personalized Medicine (SFMP) in charge of Genomics and IA in cancers. Currently he is setting up a building project dedicated on artificial intelligence and gene regulation, on behalf of a consortium of research lab in Montpellier.

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