SAVE THE DATE AND KEEP CONNECTED!

As part of Solve-RD, Solving the unsolved rare diseases, a European project H2020 (http://solve-rd.eu/) on genetic research, the Health Economics Team of the Economics Laboratory of Dijon (University of Burgundy) organise the “European Conference on the Diffusion of Genomic Medicine: Health Economics & Policy” on May 28th and 29th, 2020, in Dijon (France).

Solve RD aims to improve the diagnosis of patients with rare diseases through the development of genomic medicine. Our team is part of the task force which targets the translation of research to the patient and our contribution is to query the methodological challenges of evaluating and measuring the impact of genomic medicine. It is in this perspective of exchanges and contribution to these challenges that we organise this conference.

Here is the website of the conference: https://ecogenomics.sciencesconf.org/ You will find on it all the important information about the conference.

Do not hesitate to disseminate this newsletter widely.
If you need any further information, feel free to contact Camille Level, the engineer recruited as coordinator for this event: camille.level@u-bourgogne.fr.

SCOPE OF THE CALL FOR ABSTRACTS AND ORGANISED SESSIONS

You are kindly invited to submit an oral presentation of your research at the “European Conference on the Diffusion of Genomic Medicine: Health Economics & Policy” on May 28th and 29th, 2020, in Dijon (France) organised by the Health Economics Team of the Economics Laboratory of Dijon (University of Burgundy). This conference aims to contribute to the development of research in genomic medicine concerning its evaluation, its dissemination and the public policies accompanying this new type of medicine.

Articles in the fields of Health Economics or Public Policy Analysis will be favoured. However, this conference would be greatly enriched by multidisciplinary sharing. The following disciplines are therefore welcome, subject to dealing with, at least, one of the ten topics listed on the next page: Philosophy, Law, Linguistics and Languages, Literature, Sociology, Psychology, Ethnology, Anthropology, Geography, History and History of Thought, Management Sciences, Ethics etc. You will be asked to identify the most relevant field to which your submission relates.
The conference will embrace the following topics:
1. Preferences, expectations, representations of patients and professionals
2. Medico-economic evaluation
3. Diffusion in health systems
4. Big data: uses and risks
5. Financial access
6. Legislation, public regulations and policies for diffusion
7. Patients management and care pathway
8. Organisational and relational changes for professionals
9. Open access, access inequalities and equity
10. Dissemination to the general public

Given this conference is part of the H2020 European project “Solve-RD: Solving the unsolved Rare Diseases”, research focusing on rare diseases is one of our targets. But all others fields related to genomic medicine are welcome: pharmacogenomics, oncogenetics, screening in the general population, complex multifactorial diseases, new omic and multi-omics approaches, etc. This list is not exhaustive.

DISCOVER KEYNOTE SPEAKERS!

Holm Graessner has been Managing Director of the Rare Disease Centre, since 2010, at the University and University Hospital Tübingen, Germany www.zse-tuebingen.de. He is Coordinator of the European Reference Network for Rare Neurological Diseases (ERN-RND) www.ern-rnd.eu. In the Coordinator’s Group of the European Reference Networks, he co-leads the joint – ERN coordinators and Board of Member States - working group on Integration. Together with Olaf Riess, he coordinates the H2020 Solve-RD project on “Solving the unsolved rare diseases” www.solve-rd.eu. He received his PhD “Summa cum laude” in 2004 and, then, he obtained his MBA degree in 2008. From 2003 until now, he has been coordinating and managing more than 10 EU funded collaborative projects. The main focus of these projects are rare and neurological diseases, among them EUROSCA, MEFOPA, SENSE-PARK, MULTISYN, NEUROMICS and PROOF.

Mandy Ryan is Director of the Health Economics Research Unit at the University of Aberdeen. Her research interests centre around taking a person centered approach to valuation in health economics. She is best known for her work challenging the clinical approach to valuation that is often adopted by health economists and for developing alternative person centered approaches. She introduced discrete choice experiments (DCEs) into health economics in the early 1990s and her research has applied DCEs in a wide range of contexts to take account of the user preferences in the delivery of health care. She has recently been awarded funding by the Scottish Government to conduct an economic assessment of whether Scotland should adopt Whole Genomic Sequencing for the diagnosis of rare disorders. She will talk about her research going beyond clinical outcomes in the valuation of health care and consider its relevance to her work evaluating whole genomic sequencing.

Emmanuelle Rial-Sebbag, Lawyer, Graduate in health law (Faculty Bordeaux, France), Ph.D in Health Law (European mention, University Paul Sabatier Toulouse). She is Director of research at Inserm in health law and bioethics. She is the leader of a multidisciplinary team, Health innovations 'trajectories: bioethics challenges and impact in public health, at the Inserm/Paul Sabatier University 1027 Unit. She is an Associate lecturer in bio-law and bioethics at the University of Medicine in Toulouse (Purpan). She is involved in several research projects at National, European and International level, on the topics of biobanking and personal data, innovative therapies, biomedical research involving human beings, genetic testing and Big Data. She was the coordinator of the EUCellEX project (FP7 2013-2016, Cell-based regenerative medicine new challenges for EU legislation and governance, GA 601806, https://www.eucellex.eu/). She is leading the UNESCO Chair “Ethics, Science and Society” (https://chairee2s.hypotheses.org/).

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Be kind to our planet. Print this newsletter only when necessary.