



# FEAM Spring Conference 2016

## Precision Medicine and Personalized Health – New Dimensions

**May 20, 2016 – Kursaal Berne, Switzerland**

Hosted by

**SAMS**  Swiss Academy  
of Medical Sciences

## Precision Medicine and Personalized Health – New Dimensions

The FEAM Spring Conference 2016 will be the opportunity to hear leading experts from across Europe on the development of national and international networks, the latest research findings in specific disorders, as well as new dimensions and related ethical issues.

The aim of the Conference is to facilitate cross-sectorial discussions, to identify European research and policy opportunities and challenges, and to discuss the future activities of FEAM. It is planned to elaborate a summary of the Conference that will be widely disseminated in Europe in order to pursue the engagement of FEAM with the European biomedical community on this topic and to foster a vibrant European research environment.

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### Programme

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#### 09.00 – 09.30 Welcomes

- [Prof. Peter Meier-Abt](#) President SAMS
- [Prof. Bernard Charpentier](#) FEAM President, French Academy of Medicine
- [Dr. Gregor Häfliger](#) Vice President State Secretariat for Education, Research and Innovation

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### SESSION 1 National and International Networks

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**CHAIRS** [Prof. Bernard Charpentier](#) FEAM President, French Academy of Medicine  
[Prof. Peter Meier-Abt](#) President SAMS

#### 09.30 – 09.50 Connecting Europe for Genomic Health

[Dr Elmar Nimmesgern](#) Deputy Head of Unit, DG Research & Innovation  
E2 Innovative and Personalised Medicine, European Commission

#### 09.50 – 10.20 Big Data & Big Health: Personalized Medicine as a Paradigm Shift

[Prof. Lisette van Gemert-Pijnen](#) Center for eHealth & Wellbeing Research,  
University of Twente (NL)

10.20 – 10.45 Coffee Break

#### 10.45 – 11.05 The 1000 Genomes and Genotype-Tissue Expression (GTEx) Projects: New Results and Challenges

[Prof. Manolis Dermitzakis](#) Department of Genetic Medicine and  
Development, University of Geneva (CH)

#### 11.05 – 11.25 From Biobanking to Precision Medicine

[Prof. Andres Metspalu](#) Estonian Genome Center, University of Tartu (EST)

#### 11.25 – 11.45 Genomics-based Personalized Prevention

[Prof. Hilary Burton](#) Director PHG Foundation, Cambridge (UK)

#### 11.45 – 12.30 Discussion

12.30 – 13.15 Lunch

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## SESSION 2 Personalized Medicine in Specific Disorders

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- CHAIRS** Prof. Françoise Meunier FEAM Vice President, Belgian Academy of Medicine  
Prof. Martin Schwab Vice President SAMS
- 13.15 – 13.35 New Diagnostics in Personalized Cancer Medicine**  
Prof. Michael Neumaier Institute of Clinical Chemistry, University  
Heidelberg, Mannheim (D)
- 13.35 – 13.55 Quantified Self Devices in Neurological Disorders**  
Prof. Phillipe Ryvlin Department of Clinical Neuroscience, Centre Hospitalier  
Universitaire Vaudois, Lausanne (CH)
- 13.55 – 14.15 Metabolomics and Personalized Medicine**  
Prof. Oscar Yanes CIBERDEM & Rovira i Virgili University, Tarragona (E)
- 14.15 – 14.45 Discussion**
- 14.45 – 15.15 Coffee Break**

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## SESSION 3 Personalized Medicine – New Dimensions and Ethical Issues

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- CHAIRS** Prof. Maria do Ceu Machado FEAM Vice President, Portuguese Academy  
of Medicine  
Prof. Christian Kind President Central Ethics Committee of the SAMS
- 15.15 – 15.35 The Ethics of Personalized Medicine**  
Prof. Effy Vayena Health Ethics and Policy Lab, University of Zurich (CH)
- 15.35 – 15.55 Assessing the Human Gut Microbiota in Metabolic Diseases**  
Prof. Jens Nielsen Department of Biology and Biological Engineering,  
Chalmers University of Technology, Gothenburg (S)
- 15.55 – 16.15 The Increasing Opportunities for using Health Data  
as a Tool for Clinical Research**  
Prof. Dipak Kalra The EuroRec Institute, London (UK)

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## SESSION 4 Perspectives for FEAM

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- CHAIR** Prof. Dermot Kelleher former FEAM President,  
University of British Columbia, Vancouver
- 16.15 – 17.00 Round Table Discussion**  
Prof. Maria do Ceu Machado FEAM Vice President,  
Portuguese Academy of Medicine  
David Haerry co-chair of the Patient and Consumer Working Party  
at the European Medicines Agency  
Prof. Peter Meier-Abt President of the SAMS  
Prof. Françoise Meunier FEAM Vice President, Belgian Academy of Medicine  
Dr. Joachim Reischl VP & Head of Policy, Portfolio and Externalisation in  
Personalized HealthCare and Biomarkers, AstraZeneca  
Prof. Effy Vayena Health Ethics and Policy Lab, University of Zurich  
Prof. Andreas Wallnöfer Head Personalized Health and Translational  
Medicine, University of Basel

# ABOUT

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## SAMS – Swiss Academy of Medical Sciences

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The Swiss Academy of Medical Sciences (SAMS) was founded in 1943 and it currently comprises 232 members. The academy is committed to high-quality medicine based on ethical principles. It supports early-career researchers and engages with academia and practice. With its expert and advisory activities, the SAMS also serves policy-makers and the public.

### **Core activity: Promoting research**

The SAMS is a institution of research promotion recognised and financially supported by the federal government. It promotes high-quality research, supports early-career scientists and also focuses on less well established fields of research.

### **Core activity: Ethics**

The Central Ethics Committee of the SAMS identifies and discusses emerging ethical issues and challenges in medicine. To provide guidance for medical practice or biomedical research, it prepares guidelines and position papers and supports their implementation. The guidelines are incorporated into the Code of Conduct of the Swiss Medical Association (FMH) and thus become binding for all FMH members.

### **The SAMS as a think tank**

In its capacity as a think tank, the SAMS aims to stimulate reflection on challenging questions in medicine and to shape reasonable developments. In this context, it often collaborates closely with the Swiss Academies of Arts and Sciences.

The SAMS regularly organises and supports scientific conferences on key topics and forward-looking projects.

**SAMS**  Swiss Academy of Medical Sciences

Contact:

**Dr. Michael Röthlisberger**  
Head Department Research

### **Swiss Academies of Medical Sciences**

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## FEAM – Federation of European Academies of Medicine

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FEAM's mission is to promote cooperation between national Academies of Medicine and Medical Sections of Academies of Sciences in Europe; to provide them with a platform to formulate their collective voice on matters concerning human and animal medicine, bio-medical research, education, and health with a European dimension; and to extend to the European authorities the advisory role that they exercise in their own countries on those matters.

To underpin European biomedical policy with the best scientific advice drawn from across Europe, through the FEAM network of Academies representing over 5000 high level scientists from the whole biomedical spectrum To improve the health, safety and wealth of European citizens through research by promoting a nurturing, creative and sustainable environment for medical research and training in Europe.

FEAM's strength lies in its member Academies that give it the authority to provide an EU-wide scientific opinion on the European medical science base and evidence to underpin European bio-medical policy. The 18 FEAM Academies represent the following EU Member States: Austria, Belgium, Croatia, Czech Republic, France, Germany, Greece, Hungary, Ireland, Italy, Lithuania, Portugal, the Netherlands, Romania, Spain, Switzerland and the United Kingdom. Observers include the European Academies Advisory Council (EASAC – the European network of Academies of Sciences) and the InterAcademy Medical Panel (IAMP – the global network of Academies of Medicine).



Contact:

**Laurence Legros**  
Executive Director

### **FEAM**

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# Session 1: National and International Networks

*Chairs:*

*Prof. Bernard Charpentier, President FEAM, Paris*

*Prof. Peter Meier-Abt, President SAMS, Berne*

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## Connecting Europe for Genomic Health

Dr Elmar Nimmesgern

*Deputy Head of Unit, DG Research & Innovation, E2 Innovative and Personalised Medicine, European Commission*

### Abstract

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### CV

Elmar Nimmesgern is the deputy Head of Unit, horizontal aspects of health research in the Commission's research and innovation DG. He has been with the European Commission since 2000, following different aspects of health research. Previously he worked 5 years in a biotech/pharmaceutical company in Cambridge/MA – USA. Elmar Nimmesgern is a biochemist by training and performed cell biology research at the university of Munich and at Memorial-Sloan-Kettering Cancer Center in New York.

## Big Data & Big Health: Personalized Medicine as a Paradigm Shift

Prof. Lisette van Gemert-Pijnen

*Center for eHealth & Wellbeing Research, University of Twente (NL)*

### Abstract

Big Data are the key towards personalized medicine and healthcare. This confronts us with new challenges. What are the hopes, challenges and dangers for using Big Data to develop personalized and persuasive coaching systems? The use of Big Data for analysis and decision making requires a change of thought from knowing "why" to knowing "what". We focused on small, exact datasets and causal connections (i.e., knowing "why") in the past; now we focus on gathering or linking a large amount of (noisy) data with which we can demonstrate the presence of (unexpected) correlational connections (i.e., knowing "what"). As a result, we will obtain and apply new insights that we did not have before. Insights that can not only be lifesaving, but that can also open the door towards more personalized medicine to tailor medical decisions, medications and/or products to the individual's personal profile instead of to what is best for a group of patients.

In this presentation I will highlight a paradigm shift in using Big Data to support Health. We face new technological and societal challenges using Big Data:

- Amount of data is growing explosively.
- Transparency in decision making using automated decision rules (algorithms)
- Trust and ethics will become a key issue in data driven healthcare.
- Mobility is growing explosively, and health related issues threaten mobility (global health; infections/resistance; food, water, climate change etc)
- Our models and methods might not be up to the task to provide just-in-time, interactive and persuasive feedback, and to develop intuitive and adaptive technologies to improve self-care and to transform healthcare
- Our business models should enable production and services beyond traditional care

The presentation highlights these topics and discusses new ways for personalized healthcare.

## **CV**

Lisette is a full professor at the University of Twente in Persuasive Health Technology. She has an appointment at the University Medical Center Groningen and University of Waterloo (Canada). Lisette founded and coordinates the first Center for eHealth & Wellbeing Research ([www.ehealthresearchcenter.nl](http://www.ehealthresearchcenter.nl)). Her research & tuition focusses on persuasive designs to increase trust, engagement and adherence to technologies, persuasive health technology lab ([www.cewr.nl](http://www.cewr.nl)).

Lisette collaborates with the University of Groningen (UMCG, medical department) and with Zorginstituut Nederland (National Health Care Institute) in ePublic Health research. In Persuasive Technology she cooperates with Prof Dr H Oinas-Kukkonen, from Oulu University, Finland.

Lisette is a chief editor of the International Journal on Advances in Life Sciences and she belongs to the editorial board of Medical Informatics and Decision making. Lisette participates in the scientific board of eTelemed conferences ([www.iaria.org/conferences](http://www.iaria.org/conferences)) and the association for health informatics (NIHI) Canada ([www.nihi.ca](http://www.nihi.ca)). Lisette organized the first international conference on eHealth in the Netherlands ([www.medicine20congress.com](http://www.medicine20congress.com)), and she organizes the annually conferences "Supporting Health by Technology" ([www.healthbytech.com](http://www.healthbytech.com)).

In 2011 Lisette developed the CeHRes-Roadmap, a process guideline for development, implementation and evaluation of eHealth technologies ([www.cewr.nl](http://www.cewr.nl); papers). The roadmap is based on research in business modelling, persuasive technology and health psychology. The roadmap and its accompanied tools and instruments for development, implementation and evaluation has been used in several (inter)national eHealth projects. Lisette was editor of the first academic eHealth book for research and education, improving eHealth (2013), and contributed to several books in research methodology, dementia care and eHealth for professional education (target group applied universities).

# The 1000 Genomes and Genotype-Tissue Expression (GTEx) Projects: New Results and Challenges

Prof. Manolis Dermitzakis

*Department of Genetic Medicine and Development, University of Geneva (CH)*

## Abstract

The promise of personalized medicine cannot be achieved until we know the mechanistic relationships between genetic variation and disease risk. Molecular phenotypes inform us about genetic and environmental effects on cellular and tissue state. The elucidation of the genetic basis of gene expression and other cellular phenotypes is highly informative for the impact of genetic variants in the cell and the subsequent consequences in the organism. In this talk I will discuss recent advances in key areas of the analysis of the genomics of gene expression and cellular phenotypes in human populations and multiple tissues in projects such as GTEx and how this assists in the interpretation human disease variants. I will present results from a number of studies offering mechanistic hypotheses for the genetic effects on complex disease. These provide a great framework for the understanding of the aetiology of complex disease as well as possible ways that this knowledge can be used for risk assessment and development of treatment regimes. Finally, I will present some perspectives on how these developments are bringing us closer to the promise of personalized medicine.

## CV

Emmanouil (Manolis) Dermitzakis is currently a Professor of Genetics in the Department of Genetic Medicine and Development of the University of Geneva Medical School. He is a member of the executive board of the Institute of Genetics and Genomics in Geneva (iGE3), a member of the Swiss Institute of Bioinformatics. He obtained his B.Sc. in 1995 and M.Sc. in 1997 in Biology from the University of Crete (Greece) and his PhD in 2001 from the Pennsylvania State University in the USA, studying the evolutionary biology and population genetics of regulatory DNA in mammals and *Drosophila*. His post-doctoral work was at the University of Geneva Medical School, focusing on comparative genome analysis and the functional characterization of conserved non-genic elements. He, previously, was an Investigator and Senior Investigator at the Wellcome Trust Sanger Institute in Cambridge from 2004 to 2009. He was elected an EMBO member in 2014 and has also been named Highly Cited Researcher by ISI in 2014 and 2015. He served as the president of the Executive Board of the World Hellenic Biomedical Association (2014-2015) His current research focuses on the genetic and molecular basis of human disease. He has authored and co-authored more than 150 papers in peer-reviewed journals and many of them in journals such as *Nature*, *Science* and *Nature Genetics*, his papers have been cited more than 35,000 times and his H-index is 68. His research is supported by the Louis-Jeantet Foundation, the Wellcome Trust, the Swiss National Science Foundation, the European Commission, the Juvenile Diabetes Foundation and the US National Institutes of Health (NIH). He is also the recipient of a European Research Council (ERC) grant. He has given invited talks and keynote lectures in >120 conferences in some of the most prestigious genetics meetings and is the organizer of multiple training courses including the Wellcome Trust HapMap course and co-founder and co-organizer of the Leena Peltonen School of Human Genomics. He has served as

an analysis co-chair in the pilot phase of the ENCODE (ENCyclopedia Of Dna Elements) consortium and member of the analysis group of the Mouse Genome Sequencing Consortium and the International HapMap project. He had a leading analysis role in the extension of the HapMap (aka HapMap3 project) and is a member of the analysis group of the 1000 genomes project and a co-chair in the GTEx project. He has served in the Board of Reviewing Editors of Science (2006-2011) and eLIFE (2013-2015), and he was a Senior Editor in PLoS Genetics.

## **From Biobanking to Precision Medicine**

Prof. Andres Metspalu

*Estonian Genome Center, University of Tartu (EST)*

### **Abstract**

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### **CV**

Andres Metspalu, M.D., PhD., professor of Biotechnology and Director of the Estonian Genome Center of the University of Tartu. He was as a postdoc (IREX fellow) at Columbia University and Yale University in 1981-1982. His main scientific interests are human genomics, genetics of complex diseases and population based biobanks and their applications in translational research and precision medicine. He has published more than 300 papers and chapters. His H-index is 59.

From 1986 -1992 he was at the Estonian Biocentre as a scientific director and head of the laboratory of gene expression at University of the Tartu. He worked at EMBL, Heidelberg (as a FEBS Fellow in 1985), at MPI Molecular Genetics in W-Berlin (as a EMBO Fellow in 1988). In 1993-1994 he was at Baylor College of Medicine, Houston, Tx. as a visiting faculty with Dr. T. Caskey and in 2000 at IARC, Lyon (France), as a recipient of the IARC International Visiting Senior Scientist Award. In 2012 he took a 3 m. sabbatical leave and was working at CIG Univ. of Lausanne. From 1996 to 2008 A. Metspalu was also the founder and head of the Molecular Diagnostic Center of the Tartu University Hospital. Metspalu is the past (2006) president of the European Society of the Human Genetics and president of the Estonian SHG. He is one of the founders and directors of the P3G Consortium of Biobanks and BBMRI -ERIC. In 2010 he was elected to the Estonian Academy of Sciences.

He supervised 20 Ph.D. theses. He has served and is serving in several national and international committees (ERC panel, P3G director, SAC in Science Europe), editorial boards (Clinical Genetics) and has received among other awards and honors the Order of the Estonian Red Cross 3rd Class and L'Ordre des Palmes Academiques from the Republic of France. From 2010 he has Doctor Honoris Causa from Vilnius University.



# Genomics-based Personalized Prevention

Prof. Hilary Burton

*Director PHG Foundation, Cambridge (UK)*

## Abstract

Health systems today are universally grappling with the simultaneous challenges of ageing populations, greater patient expectation, and seemingly endless scientific and technological advances almost always within a context of tight fiscal limits. In such a climate, prevention is characteristically acknowledged as an important part of the solution. Classical public health programmes aimed at population level have an important role to play, but, increasingly, personalised prevention will provide opportunities and an extra dimension to the Precision Medicine and Personalised Health agenda.

Effective personalised prevention depends on an understanding of individual risk and the tailoring of interventions to reduce risk. Good examples of the potential of this approach exist now for single gene disorders and increasingly for genetic subsets of disease such as some cancers or heart disease. In the future we will understand more about the genomic basis of chronic disease, individual interactions with diet, environmental pollutants, medicines, infectious agents and vaccines. Set alongside other individual approaches to disease prevention, including, for example the increasing uptake of digital devices to monitor lifestyle and physiology and the increasing emphasis on personal empowerment, we can envisage societies and health systems increasingly moving toward a personalised approach to disease prevention. However, to be effective this must be accompanied by improvements in the public's health literacy, attention to a range of ethical, legal and social issues, education of professionals including a cultural and educational shift for public health practitioners, and changes to health systems,

## CV

Dr Hilary Burton is the Director and one of the founder members of the PHG Foundation and a Fellow of Hughes Hall, Cambridge. The PHG Foundation is a not for profit organisation with a special focus on how genomic and other technologies can provide more effective personalised healthcare and improve population health <http://www.phgfoundation.org/>. Qualified in medicine at Oxford University, Hilary subsequently trained in public health in the Eastern Region and worked as a consultant in Cambridge.

Since 1997 at the PHG Foundation Hilary has focused on the genomics context for population health, and, in particular, has led national work on the implementation of new technologies in mainstream UK health services. She has been closely involved in the implementation of genomics technologies for screening programmes in the contexts of carrier screening, antenatal or newborn screening and has worked with major European Commission research programmes looking at the potential for susceptibility testing for common cancers and cardiovascular disease.

Leading the PHG Foundation team has enabled a multidisciplinary approach to this work. Key themes at present for prevention include the importance of data collection and sharing, personal empowerment and consent, the education of health professionals and the resolution of many ethical, regulatory and social issues.

Throughout her time at the PHG Foundation Hilary has been closely involved in genomics policy work in the UK. In 2011/2 she sat on the UK Government Human Genomics Strategy Group and is currently a member of the UK Genetic Testing Network Clinical and Scientific Advisory Group, Joint Committee on Genomic Medicine of the Medical Royal Colleges, the Council of the British Society for Genetic Medicine and the Health Education England Genetics Advisory Board. She is also a founder member of a European group on public health genomics, led from the Università Cattolica del Sacro Cuore in Rome.

## **Session 2: Personalized Medicine in Specific Disorders**

*Chairs:*

*Prof. Françoise Meunier, Vice President FEAM, Brussels*

*Prof. Martin Schwab, Vicepresident SAMS, Zurich*

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### **New Diagnostics in Personalized Cancer Medicine**

Prof. Michael Neumaier

*Institute of Clinical Chemistry, University Heidelberg, Mannheim (D)*

#### **Abstract**

The deeper understanding of pathobiochemical principles in the development and progression of malignant disease and deciphering the affected pathways are currently enabling the design of specific targeted therapies for an increasing number of tumour entities. To make proper use of such therapies, comprehensive and detailed molecular analyses designated “companion diagnostics” have to be performed first for patient stratification.

Methodological advances based on digital PCR and massive parallel DNA sequencing allow for a highly detailed characterization of molecular defects in the tumour genome and epigenome taking into account a certain degree of its molecular heterogeneity. During progression, molecular defects may be selected for to display molecular tumour profiles that are not only different from the primary tumour, but also provoke changes in therapeutic strategies for the patient. A number of recently described techniques may be employed depending on the clinical question, and their promises and challenges will be discussed.

#### **CV**

Michael Neumaier is a Clinical Chemist and Laboratory Physician working as a university professor at the University of Heidelberg. In 2002, he was appointed director of the Institute for Clinical Chemistry at the University Hospital Mannheim and also holds the

chair for Clinical Chemistry at the University of Heidelberg, Germany. He has been engaged in quality assessment and management systems for laboratory diagnostics since many years. Since 1998, he has been setting-up and organizing molecular EQA programs in Germany and Europe with more than 350 laboratories participating biannually in nucleic acids isolation, genotyping and sequencing exercises. Since 2000, he acts, by appointment of the German Chamber of Physicians, as a director of the national EQA system for medical laboratories organized and run by the Reference Institute for Bioanalytics (RfB) in Bonn, Germany. Since 2009 he is chairman of the section for Molecular Diagnostics of the Germany Society for Clinical Chemistry and Laboratory Medicine (DGKL). In 2011 he was appointed chairman of the scientific board of the RfB, of which he has been a member for many years. Currently, he acts as the Vicepresident of the DGKL in preparation for the presidential term starting in 2014. His main scientific interests are colorectal tumorigenesis, pathobiochemistry of malignant disease and the development of methods for the molecular diagnostics of cancer. His interest also includes assessment of biomolecular quality in complex clinical biospecimens.

## **Quantified Self Devices in Neurological Disorders**

Prof. Phillippe Ryvlin

*Department of Clinical Neuroscience, Centre Hospitalier Universitaire Vaudois, Lausanne (CH)*

### **Abstract**

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### **CV**

Philippe Ryvlin is Professor of Neurology and Chair of the Department of Clinical Neurosciences at the University Hospital of Lausanne (CHUV), Switzerland, and Director of the Epilepsy Institute (IDEE) in Lyon, France. He is President of the European Epilepsy Monitoring Association (EEMA), co-Chair of the Epilepsy Advocacy Europe Joint Task Force, founder of the European Network for Epilepsy Research (ENER), and coordinator of the European pilot network of reference centres in refractory epilepsy and epilepsy surgery recently granted by the European Union (E-PILEPSY). He is the author or co-author of over 200 PubMed referenced papers on topics primarily related to epilepsy surgery, anti-epileptic treatments and Sudden Unexpected Death in Epilepsy (SUDEP). At CHUV, Philippe Ryvlin has developed NeuroTech, a clinical research infrastructure dedicated to the evaluation of novel technologies in patients with neurological disorders, with emphasis on mobile and connected devices as well as assisting robots.

# Metabolomics and Personalized Medicine

Prof. Oscar Yanes

*CIBERDEM & Rovira i Virgili University, Tarragona (E)*

## Abstract

Metabolomics is defined as the comprehensive qualitative and quantitative analysis of metabolites in living organisms. Metabolites are the functional output of cellular reactions and therefore more closely correlate with phenotype. Here an untargeted metabolomics platform will be detailed that provides a method for identifying cellular pathways that are perturbed during disease. The application of the technology to uncover the metabolic derangements that determine the long-term health risks of hyperinsulinaemic androgen excess in prepubertal and pubertal girls will be discussed.

## CV

Oscar Yanes received his B.A. and Ph.D. degrees in biochemistry from the Autonomous University of Barcelona (Spain). In 2007 he joined The Scripps Center for Metabolomics and Mass Spectrometry (La Jolla, California) headed by Dr. Gary Siuzdak. Since January 2011 he is the scientific co-ordinator of the Metabolomics Platform of the Spanish Biomedical Research Centre in Diabetes and Associated Metabolic Disorders (CIBERDEM) and Assistant Professor at the Universitat Rovira i Virgili (Tarragona, Spain), where he also leads the Yanes Lab group ([www.yaneslab.com](http://www.yaneslab.com)).

He has long experience in developing new technologies, methods and applications in mass spectrometry-based metabolomics. His lab now focuses on understanding metabolic dysregulations in disease through integrating mass spectrometry and NMR-based metabolomics with other omic technologies such as transcriptomics and proteomics.

## Session 3: Personalized Medicine – New Dimensions and Ethical Issues

*Chairs:*

*Prof. Maria do Ceu Machado, Vice President FEAM, Lisbon*

*Prof. Christian Kind, President Central Ethics Committee SAMS, St. Gallen*

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### The Ethics of Personalized Medicine

Prof. Effy Vayena Health

*Ethics and Policy Lab, University of Zurich (CH)*

#### Abstract

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#### CV

Effy Vayena, Ph.D., studied Medical History and Bioethics at the University of Minnesota (USA) and completed her habilitation in Bioethics and Health Policy at the University of Zurich. From 2000- 2007 she worked at the World Health Organization (WHO), focusing on ethical and policy issues relating to reproductive health, and assisted reproduction as well as on health research ethics. She remains at consultant to WHO and is visiting faculty at the Harvard [Center for Bioethics](#), Harvard Medical School. In 2015–2016, she is Fellow at the [Berkman Center for Internet and Society](#) at Harvard Law School. In 2015 she was named a Swiss National Science Foundation (SNSF) Professor of Health Policy and leads the newly-established [Health Ethics and Policy Lab](#) in the Department of Public Health at the EBPI, University of Zurich.

Her current research focus is on ethical and policy questions in personalized medicine and digital health. At the intersection of multiple fields, she relies on normative analyses and empirical methods to explore how values such as freedom of choice, participation and privacy are affected by recent developments in personalised medicine and in digital health. She is particularly interested in the issues of ethical oversight of research uses of big data, ethical uses of big data for global health, as well as the ethics of citizen science. Using the ethics lens in innovative ways, her work aims to provide concrete policy recommendations and frameworks that facilitate the use of new technologies for a better and more just health.

# Assessing the Human Gut Microbiota in Metabolic Diseases

Prof. Jens Nielsen

*Department of Biology and Biological Engineering, Chalmers University of Technology, Gothenburg (S)*

## Abstract

The composition of the human gut microbiome has been shown to be correlated with a wide range of different diseases, e.g. type 2 diabetes, cardiovascular disease, depression and malnutrition. The gut microbiome can be analyzed using metagenome analysis of DNA extracted from stool samples, and this allows for correlation of species abundance with e.g. blood chemistry markers. In order to gain more mechanistic insight into how the gut microbiome impacts metabolism of the human body it is, however, necessary to analyze the metabolism of the different gut bacteria and how they interact both with each other and with host metabolism. To gain such insight we are developing detailed metabolic models for 100+ gut bacteria, so-called genome-scale metabolic models (GEMs), and we are using these for simulation of how the gut microbiome metabolism respond to changes in diet and other environmental factors. By using metagenomics sequencing data from the gut microbiome of patients with different diseases, e.g. arteriosclerosis and type 2 diabetes, we can simulate how the gut microbiome metabolism may impact disease development. Through the combination of the bacterial GEMs and metagenomics data we have identified enriched metabolic functions in the microbiome, and based on this we point to novel prospective biomarkers for disease development. We are further integrating metagenomics information into predictive metabolic models that have the prospect for simulation of how the gut microbiome respond to diet. Our analysis clearly show that the gut microbiome may play a very important role in disease development, and possible also on drug response, even to immuno-therapies used for cancer treatment, and that stratification of the gut microbiome may therefore be essential for proper treatment of a wide range of diseases in the future.

## CV

Jens Nielsen has an MSc degree in Chemical Engineering and a PhD degree (1989) in Biochemical Engineering from the Danish Technical University (DTU), and after that established his independent research group and was appointed full Professor there in 1998. He was Fulbright visiting professor at MIT in 1995-1996. At DTU he founded and directed Center for Microbial Biotechnology. In 2008 he was recruited as Professor and Director to Chalmers University of Technology, Sweden, where he is currently directing a research group of more than 50 people. At Chalmers he established the Area of Advance Life Science Engineering, a cross departmental strategic research initiative and was founding Head of the Department of Biology and Biological Engineering, which now encompass more than 170 people. Jens Nielsen has published so far more than 550 papers that have been cited more than 18,000 times (current H-factor 65), co-authored more than 40 books and he is inventor of more than 50 patents. He has founded several companies that have raised more than M25EUR in venture capital. He has received numerous Danish and international awards including the Nature Mentor Award, and is member of several academies, including the National Academy of Engineering in USA,

the Royal Swedish Academy of Science, the Royal Danish Academy of Science and Letters, the Royal Swedish Academy of Engineering Sciences and the American Academy of Microbiology. He is a founding president of the International Metabolic Engineering Society.

## **The Increasing Opportunities for Using Health Data as a Tool for Clinical Research**

Prof. Dipak Kalra

*The EuroRec Institute, London (UK)*

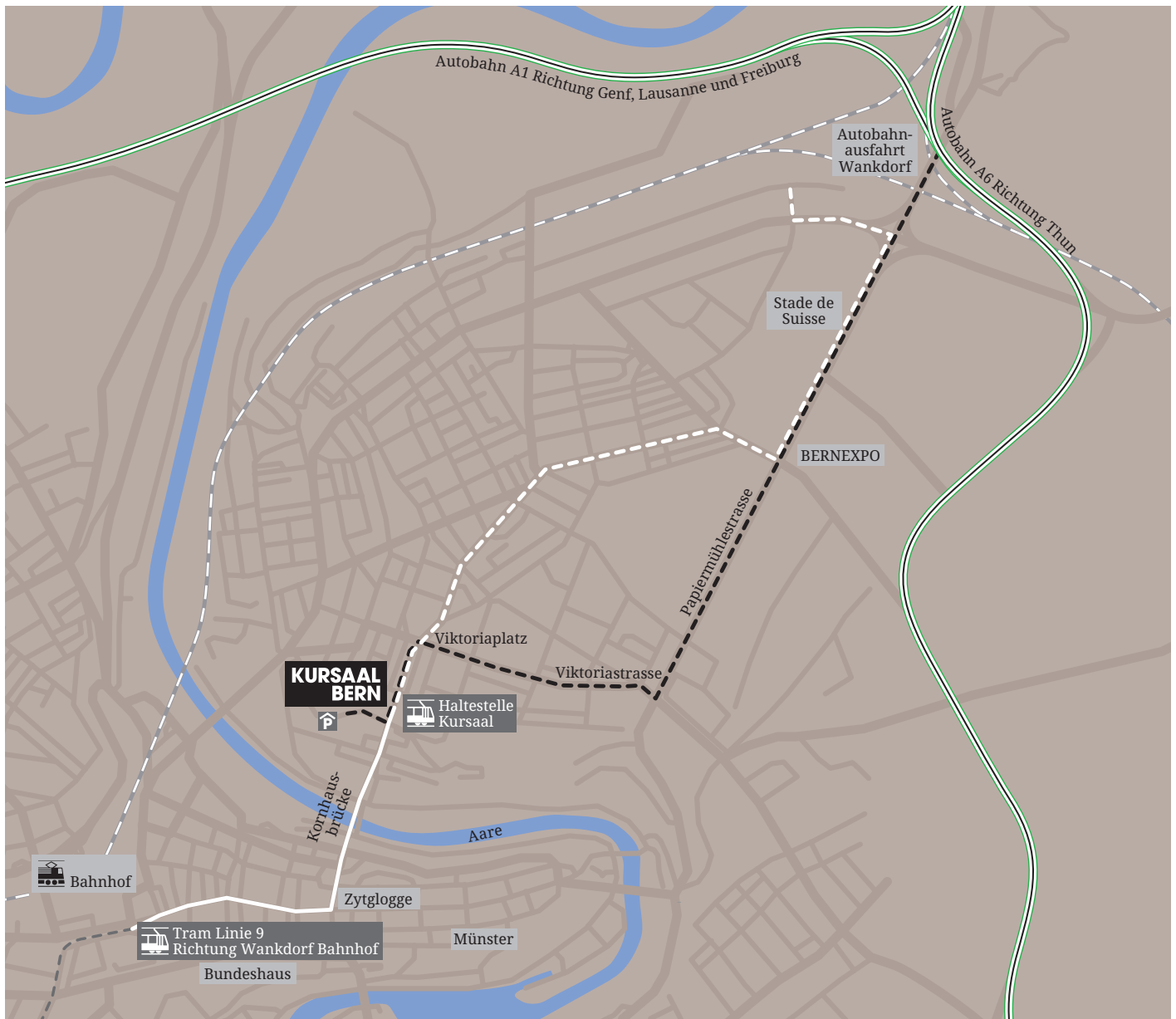
### **Abstract**

Patient identification for recruitment into Phase 3 clinical trials is still undertaken in *ad hoc* ways, is slow and leads to avoidable protocol amendments that delay or even abort valuable studies. The secure remote querying of de-identified hospital electronic health record (EHR) information has the potential to accelerate trials and help hospitals to boost recruitment numbers. This presentation will explain how a European public-private project, EHR4CR, sponsored by the Innovative Medicines Initiative (IMI), has developed a trustworthy approach to achieving this, which is now being scaled up. A second IMI project, EMIF, is developing a platform for the federated querying of multiple research data sources across Europe, to enable data source discovery and large scale (big) data research. Such big data research is already establishing the pathophysiological role of newly discovered biomarkers, and being used to generate distributed research cohort profiles on a scale beyond the scope of any single data source. The capability for such large scale population sub-profiling and stratification is an essential pre-requisite to scaling up the adoption and benefits realisation from precision medicine. Governance of such a Europe-wide research ecosystem is vital for public trust, and a new not for profit institute has been formed to promote good governance practices when EHR data are reused for research.

### **CV**

Dipak Kalra, PhD, FRCGP, FBCS, is President of The European Institute for Innovation through Health Data (i~HD). He plays a leading international role in research and development of EHR architectures and systems, including approaches to harmonise clinical meaning and protect privacy, and had led the development of key international standards on EHR interoperability. Dipak leads the Managing Entity (EuroRec) for a €16m Innovative Medicines Initiative on the re-use of electronic health record information for clinical research, EHR4CR, alongside ten global pharmaceutical companies. EuroRec is also a partner in another IMI project, EMIF, on the development of a European clinical research platform federating multiple population health and cohort studies. Dipak also leads an EU Network of Excellence on semantic interoperability, and is a partner in other EU projects on the sustainability of interoperability assets and the transatlantic sharing patient summaries. Dipak is Clinical Professor of Health Informatics at University College London, United Kingdom, a Director of the openEHR Foundation, and a member of standards bodies including CEN, ISO and HL7-UK.

# ANFAHRTSPLAN / LOCATION MAP / PLAN D'ACCÈS



## Anreise mit der Bahn:

Ab Hauptbahnhof Tram Nr. 9 Richtung «Wankdorf Bahnhof» (Haltestelle «Kursaal»)

## Anreise mit dem Auto:

- Autobahnausfahrt «Bern-Wankdorf»,
- geradeaus Richtung «Zentrum» – Papiermühlestrasse
- rechts einspuren, an der 3. Kreuzung rechts in die Viktoriastrasse abbiegen (Hotel Allegro/Kursaal sind angeschrieben)
- am Viktoriaplatz links in die Kornhausstrasse abbiegen
- Das Hotel Allegro/Kursaal befindet sich auf der rechten Seite

## Parking

Die Parkgebühr für 24 Stunden Parking beträgt CHF 26.–

## Arriving by train:

From central railway station Tram No. 9 direction «Wankdorf Bahnhof» (stop «Kursaal»)

## Arriving by car:

- Highway exit «Bern-Wankdorf»,
- follow the signage «Zentrum» – Papiermühlestrasse
- follow the street until 3rd crossing, turn right into Viktoriastrasse and follow signage Hotel Allegro/Kursaal
- at Viktoriaplatz turn left into Kornhausstrasse
- Hotel Allegro/Kursaal is situated on the right side

## Parking

The parking fee for 24 hours is CHF 26.–

## Arrivée en train:

De la gare centrale prendre le tram n° 9 direction «Wankdorf Bahnhof» (arrêt «Kursaal»)

## Arrivée en voiture:

- prendre la sortie d'autoroute «Bern-Wankdorf»
- suivre tout droit la direction «Zentrum» par la rue «Papiermühlestrasse»
- serrer à droite, au 3ème croisement tourner à droite dans la rue «Viktoriastrasse» (l'hôtel Allegro et le Kursaal sont signalés par des panneaux)
- sur la place «Viktoriaplatz» tourner à gauche dans la rue «Kornhausstrasse»
- l'hôtel Allegro et le Kursaal se trouvent du côté droit

## Parking

Les frais de parking pour 24 heures sont de CHF 26.–