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Conference: Building genomics: genomDE – National and European initiatives

Monday 30 November, 2020

Digital event

Welcome Speech by the German Federal Ministry of Health

Mr Jens Spahn

German Health Minister (MoH)

Jens Spahn has been Federal Minister of Health since 2018. After training as a banker, he was Parliamentary State Secretary to the Federal Minister of Finance from 2013 to 2018. He has been a Member of the German Bundestag since 2002.

Welcome Speech by the European Commission

Ms Elisa Ferreira

European Commission Commissioner for Cohesion and Reforms (EC)

Ms Ferreira is the Vice-Governor of Banco de Portugal (Central Bank). Ms Ferreira is also the Portugal's representative at the Supervisory Board of the Single Supervisory Mechanism (SSM - ECB). Ms Ferreira has been Member of the European Parliament and the Portuguese Parliament, as well as Minister for Planning (spatial and Regional Development) and Minister for Environment in the Portuguese Government.

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Speech of '1+Million Genomes' Initiative

Prof. Dr. Astrid Vicente

Vice-chair of the International Consortium for Personalized Medicine (ICPerMed)

Astrid M. Vicente is a senior researcher in biomedical sciences and public health, and Head of the Department of Health Promotion and Non-Communicable Disease Prevention at the National Institute of Health Doutor Ricardo Jorge, in Lisbon, Portugal. She is also an invited Associate Professor at the Faculty of Sciences, University of Lisbon. As a researcher, she has contributed extensively to the field of genomics of complex disorders, focusing mainly on brain disease. Astrid Vicente is currently a Vice-chair of the International Consortium for Personalized Medicine (ICPerMed), and is the representative of Portugal in the 1+M Genomes initiative, where she is a member of the Coordination Group.

Speech of the Concept of genomDE: a patient centered approach

Ms Dagmar Friese

Head of Division “Biotechnological Innovation, Nanotechnology and Genetic Engineering” of the German Health Ministry

Dagmar Friese, Pharmacist, Studies in Experimental Pharmacology and Toxicology; previously worked as scientist in cancer research in the field of chemical carcinogenesis; until 2001 employed as scientific officer in regulatory affairs at the Federal Institute of Drug and Medical Devices (BfArM); joined the German Health Ministry in 2001 and before taking a leading position in the ministry worked as consultant at the Permanent Representation of Germany to the EU (2006) and as seconded national expert at the European Commission, DG Research, until 2008.

Since 2009 Head of Division “Biotechnological Innovation, Nanotechnology and Genetic Engineering”; present responsibilities are general affairs in innovative biotechnology and issues of biopharmaceuticals, including advanced therapy medicinal products, questions of principle in life sciences, of genetic engineering and nanotechnology of importance for the process of drug discovery and development.

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Prof. Dr. Thomas Berlage

Head of Digital Health" department at Fraunhofer Institute for Applied Information Technology FIT

Thomas Berlage has been Professor of Life Science Informatics at RWTH Aachen University since 2002 and heads the "Digital Health" department at the Fraunhofer Institute for Applied Information Technology FIT in Sankt Augustin. There, solutions for data integration in drug research and medicine, for data analysis, especially of image data, and for digital patient-oriented platforms are being researched. The division also makes a significant contribution to the Fraunhofer "Medical Data Space" initiative and the Fraunhofer "Big Data and AI" alliance. Prof. Berlage is a member of the Comprehensive Diagnostic Center Aachen and advises the Aachen Biobank. He was also involved in the DFG Clinical Research Group 217 on "Toponomics of Liver Diseases".

Speech of Status quo of German genomic initiatives

Prof. Dr. Heiko Krude

Coordinator of the Translate-Namse innovation fund project

As Professor of Experimental Pediatric Endocrinology, his main interest for 25 years has been in congenital rare diseases of the endocrine system. Prof. Dr. Heiko Krude has been involved in the initial description of several new diseases. He was a founding member of the Berlin Centre for Rare Diseases. Since 2017, he has been coordinating the Translate-Namse innovation fund project, which aims primarily to improve the diagnosis of rare disease patients and will be completed in March 2021.

Prof. Dr. Olaf Rieß

Director of the Institute of Human Genetics and Applied Genomics, University of Tübingen

Prof. Dr. Olaf Rieß is full Professor of Human Genetics and head of the Institute of Medical Genetics and Applied Genomics at the University of Tübingen. He and has more than 20 years of experience in genetically caused disorders. He has been coordinator of numerous international, European and national funded consortia and he has published more than 250 papers.

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Prof. Dr. Nisar Malek

Founder of the Centre for Personalised Medicine Tübingen, Spokesperson of the ZPM Association Baden-Württemberg

Prof. Dr. N. Malek, Medical Director of the Department of Internal Medicine at the University Hospital Tübingen and Head of the Department of Internal Medicine 1 (Gastroenterology, Gastrointestinal Oncology, Hepatology, Infectiology and Geriatrics) as well as Deputy Director of the Comprehensive Cancer Center Tübingen-Stuttgart and Co-Speaker SFB/TR 209-Liver Cancer. Founder of the Centre for Personalised Medicine Tübingen in 2015 and spokesperson of the ZPM Association Baden-Württemberg since 2017. His research focus is the development of personalised treatment approaches for tumours of the gastrointestinal tract.

Prof. Dr. Stefan Fröhling

Managing Director of the National Centre for Tumour Diseases (NCT) Heidelberg

Stefan Fröhling is Managing Director of the National Centre for Tumour Diseases (NCT) Heidelberg and heads the Department of Translational Medical Oncology at the NCT Heidelberg and the German Cancer Research Centre (DKFZ). His scientific and clinical work focuses on the comprehensive molecular and functional characterisation of cancers and the design of clinical trials to investigate the efficacy of novel, personalised cancer treatments. Stefan Fröhling is Co-Director of the NCT research programme "Molecular Diagnostics", the research platform "Cancer Genome Analysis" of the German Cancer Research Consortium (DKTK), served on the Board of the European Hematology Association (EHA) and is a member of the Board of Directors of Cancer Core Europe (CCE).

Prof. Dr. Jürgen Wolf

Medical Director of the Centre for Integrated Oncology (CIO) at the University Hospital of Cologne

Jürgen Wolf is a Medical Oncologist from the University Hospital of Cologne (UHC). He holds a Professorship for Interdisciplinary Translational Oncology at the University of Cologne (UC). At UHC he is the Medical Director of the Center for Integrated Oncology (CIO) and member of the Executive Board of the CIO Aachen Bonn Cologne Düsseldorf. He is also co-founder and speaker of the national Network Genomic Medicine (nNGM) Lung Cancer.

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Prof. Dr. Rita Schmutzler

Head of the Centre for Familial Breast and Ovarian Cancer at the University Hospital of Cologne, Coordinator of the Consortium for Familial Breast and Ovarian Cancer

Prof. Rita Schmutzler is head of the Centre for Familial Breast and Ovarian Cancer at the University Hospital of Cologne and is coordinator of the Consortium for Familial Breast and Ovarian Cancer consisting of 23 university centres. She has promoted the concept of risk-adapted prevention and is, among other things, spokesperson for the target paper "Risk-adapted early detection", which was drawn up under the auspices of the BMG within the framework of the National Cancer Plan. Under her leadership, the consortium has established a nationwide knowledge-generating and quality-assured care concept, which is being evaluated by means of accompanying documentation. The entire clinical care path from the identification of affected persons, individualised counselling and risk prediction to personalised prevention is mapped.

Speech of Genomic State of Art in 4 European Countries

Prof. Dr. Søren Brunak

Research Director at the Novo Nordisk Foundation Center for Protein Research at University of Copenhagen

Søren Brunak is professor and Research Director at the Novo Nordisk Foundation Center for Protein Research at University of Copenhagen. He is a leading pioneer in the biomedical sciences through invention and introduction of new computational strategies for analysis of biological data for use in molecular biology, medicine and biotechnology, including machine learning approaches. Søren Brunak is an EMBO member, and also member of the Royal Danish Academy of Sciences and Letters and the Royal Swedish Academy of Sciences.

Prof. Dr. Alfonso Valencia

Head of the Spanish node of the European Infrastructure for Life-Science Information,ELIXIR

Alfonso Valencia is a Biologist by training with a Ph.D. in Biochemistry and Molecular Biology. He is ICREA Research Professor and Director of the Life Sciences Department at the Barcelona Supercomputing Centre (BSC), Director of the Spanish National Bioinformatics Institute (INB) and head of the Spanish Node of the European Bioinformatics Infrastructure ELIXIR. He is a member of the European Molecular

Biology Organisation (EMBO), and former President of the International Society for Computational Biology (ISCB).

Prof. Dr. Aarno Palotie

Research director of the Human Genomics program at FIMM-HiLife

Professor Aarno Palotie, M.D., Ph.D. is the research director of the Human Genomics program at FIMM-HiLife. He is also a faculty member at the Center for Human Genome Research at the Massachusetts General Hospital in Boston and associate member of the Broad Institute of MIT and Harvard. He has a long track record in human disease genetics. He has hold professorships and group leader positions at the University of Helsinki, UCLA and Wellcome Trust Sanger Institute. He has also been the director of the Finnish Genome Center and Laboratory of Molecular Genetics in the Helsinki University Hospital. He is currently the director of the large genome health project FinnGen.

Prof. Dr. Han Brunner

Head of department of the Nijmegen and Maastricht University centers for human genetics

Han Brunner is a clinical geneticist who specializes in the diagnosis, and the counseling of patients and families with neurodevelopmental disorders such as autism and severe intellectual disability.
He is head of department of the Nijmegen and Maastricht University centers for human genetics.
His departments have been among the first to implement exome sequencing as a major tool in the diagnostic process for a wide range of developmental problems.
Using the collected genomic information his group has elucidated a number of the fundamental questions about the causes of neurodevelopmental problems. These research findings inform public health strategies, as well as professional guidelines.

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Round tables. Panel discussion of Scientific Approach

Moderation

Prof. Dr. Rita Schmutzler

Head of the Centre for Familial Breast and Ovarian Cancer at the University Hospital of Cologne, Coordinator of the Consortium for Familial Breast and Ovarian Cancer

Prof. Rita Schmutzler is head of the Centre for Familial Breast and Ovarian Cancer at the University Hospital of Cologne and is coordinator of the Consortium for Familial Breast and Ovarian Cancer consisting of 23 university centres. She has promoted the concept of risk-adapted prevention and is, among other things, spokesperson for the target paper "Risk-adapted early detection", which was drawn up under the auspices of the BMG within the framework of the National Cancer Plan. Under her leadership, the consortium has established a nationwide knowledge-generating and quality-assured care concept, which is being evaluated by means of accompanying documentation. The entire clinical care path from the identification of affected persons, individualised counselling and risk prediction to personalised prevention is mapped.

Participants

Prof. Dr.Melanie Börries

Chair for Medical Bioinformatics (W3 professorship) at the University of Freiburg, Head of the Institute for Medical Bioinformatics and Systems Medicine at the University Hospital Freiburg

Prof. Dr. Dr. Melanie Börries, physician and cell biologist, has held the chair for Medical Bioinformatics (W3 professorship) at the University of Freiburg since 2019 and heads the Institute for Medical Bioinformatics and Systems Medicine at the University Hospital Freiburg.
As spokesperson of the Molecular Tumour Board of the University Hospital Freiburg, she and her team are responsible for the analysis of the sequencing data. In the framework of the Medical Informatics Initiative, she leads in the consortium MIRACUM Use Case 3 " From Knowledge to Action - Support for Molecular Tumor Boards" with the aim to create a generic framework that supports all steps from the analysis of the omics data, their interpretation leading to a final therapeutic decision in the MTBs, to their documentation in the electronic health records of all MIRACUM partner clinics.

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Prof. Dr. Hanno Glimm

Managing Director and Head of the Department “Translational Medical Oncology” at the National Center for Tumor Diseases (NCT) in Dresden

Hanno Glimm is Managing Director and Head of the Department “Translational Medical Oncology” at the National Center for Tumor Diseases (NCT) in Dresden and the Research Group “Translational Functional Cancer Genomics” at the DKFZ in Heidelberg. After studying medicine in Cologne, clinical specialization in Internal Medicine and Hematology/Oncology at the University in Freiburg and research training at the Terry Fox Laboratory in Vancouver, he became full professor of Translational Oncology and Hematology at the NCT Heidelberg before moving to Dresden in 2018.

Prof. Dr. Albrecht Stenzinger

Deputy Director of the Institute of Pathology (IPH), Head of the IPH Center for Molecular Pathology (CMP)

Albrecht Stenzinger is Professor of Molecular Tumor Pathology, Deputy Director of the Institute of Pathology (IPH), as well as the Head of the IPH Center for Molecular Pathology (CMP) and Section Head for Molecular Diagnostics and Biomarker Development at the Institute of Pathology, University Hospital Heidelberg, Germany.
He is holding an MD degree from the University of Giessen (Germany), completed his residency and fellowship training in pathology at the Charité University Hospital in Berlin and the University Hospital Heidelberg (Germany) and is a board-certified surgical pathologist and senior attending. Albrecht received postdoctoral training at the University of Heidelberg, Germany and Massachusetts General Hospital/Harvard Medical School, USA. He has a broad expertise in molecular pathology and works in the field of translational research and genetics of lung cancer.

Dr. Holm Graessner

Managing Director of the Rare Disease Centre the University and University Hospital Tübingen, Coordinator of the European Reference Network for Rare Neurological

Dr. Holm Graessner, Tübingen, Germany, is Managing Director of the Rare Disease Centre the University and University Hospital Tübingen, Germany. Furthermore, he is the Coordinator of the European Reference Network for Rare Neurological. In the EU flagship Solve-RD project on “Solving the unsolved rare disease” we develop and implement novel concepts and approaches to tackle the issue of the high percentage of molecularly unsolved rare disease patients. Aspects

of Solve-RD that might serve as a a blueprint for GenomDE are: (a) work in interdisciplinary networks that bring together clinical and data-scientific expertise, (b) establish and use appropriate data structures and processes for massive analysis and data sharing that are big data compatible and (c) tailored disease specific omics approaches.

Round tables. Panel discussion of Medical Approach

Moderation

Prof. Dr. Brigitte Schlegelberger

Dept. of Human Genetics, Hannover Medical School (MHH) and President of the German Society of Human Genetics

Brigitte Schlegelberger, MD, head of the Dept. of Human Genetics, Hannover Medical School (MHH) and President of the German Society of Human Genetics. Using state-of-the-art techniques her research focuses on the identification of novel candidate genes for hereditary malignancies aiming to translate the increasing knowledge into personalized patient care, i.e. genetic counselling of diseased and healthy family members and guiding risk-adapted preventive measures. Moreover, Brigitte Schlegelberger leads the German Genetic Reference Center for childhood leukemia serving the prospective multi-center clinical trials ALL-BFM and EWOG-MDS, that use the identified genetic markers for risk stratification.

Participants

Prof. Dr. Thomas Klopstock

Senior physician at the Friedrich-Baur-Institute at the Neurological Clinic of the Ludwig-Maximilians-University

Prof. Thomas Klopstock is a neurologist at the Friedrich-Baur-Institute, Neurological Clinic of the Ludwig-Maximilians-University Munich. He specialises in neurogenetic diseases, especially mitochondrial diseases, hereditary ataxias, and diseases with iron storage in the brain. He is spokesman of the German Network for Mitochondrial Diseases mitoNET, spokesman of the international consortium TIRCON (Treat Iron-Related Childhood-Onset Neurodegeneration) and spokesman of the Speakers' Council of all BMBF-funded German research networks for rare diseases. His scientific focus is on improving the diagnosis of rare diseases using modern molecular methods (e.g. exome or genome sequencing) including the identification of new candidate genes, as well as the development of new therapeutic approaches and their investigation in clinical studies.

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Dr. Lena Illert

Oncologist and managing senior physician at the Department of Internal Medicine of the University Hospital Freiburg

Mrs. Priv. Doz. Dr. Lena Illert, oncologist and managing senior physician at the Department of Internal Medicine of the University Hospital Freiburg is spokesperson of one of the largest molecular tumour boards in Germany. Dr. Illert also heads a competitive translational research group and is a principal investigator of multiple early phase clinical trials. As medical co-director of the Comprehensive Cancer Center Freiburg, she is responsible for the interdisciplinary care of oncological patients at a German Cancer Aid-funded top centre. Her aim is to characterise the functional relevance of the identified abberation and to be able to offer each oncological patient a molecularly appropriate, clinically meaningful, personalised therapy option according to the latest scientific findings and to implement this in an interdisciplinary manner in the context of studies.

Prof. Dr. Wilko Weichert

Chair for Pathology at the Technical University in Munich

Wilko Weichert is holding the Chair for Pathology at the Technical University in Munich. He is a member of the Board of Directors of the German Society of Pathology and serves as appointed German Expert Advisor for Molecular Biomarkers at the European Medical Agency (EMA). His research focuses on tissue based molecular pathology for the discovery, validation and clinical implementation of novel diagnostic and predictive genomic and proteomic biomarkers guiding innovative new therapeutic concepts in oncology within clinical trials and routine care.

Prof. Dr. Evelin Schröck

Director of the Institute for Clinical Genetics, Faculty of Medicine Carl Gustav Carus, TU Dresden, as Co-Director of the Core Unit for Molecular Tumor Diagnostics at the National Center for Tumor Diseases in Dresden

Evelin Schröck, MD, Professor for Clinical Genetics, serves as Director of the Institute for Clinical Genetics, Faculty of Medicine Carl Gustav Carus, TU Dresden, as Co-Director of the Core Unit for Molecular Tumor Diagnostics at the National Center for Tumor Diseases in Dresden and as Max-Planck-Fellow of the Max-Planck-Society and at the Max-Planck-Institute of Molecular Cell Biology and Genetics, Dresden.
Patients with rare diseases require a genomic diagnostics test as a first tier approach. The group aims to reach the molecular diagnosis for

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patients with neurodevelopmental disorders and with genetic tumor risk syndromes using multiomics and cell biology. Evelin Schröck actively supports several initiatives to improve medical care and to implement genomic approaches for rare diseases in routine medicine today (e.g. ERN-GENTURIS, NCT/DKTK-MASTER, DRESDEN-concept Genome Center).

Round tables. Panel discussion of Patients centred Approach

Moderation

Prof. Dr. Eva Winkler

Head of the research focus "Ethics and Patient Orientation" at the National Centre for Tumour Diseases

Eva Winkler is Heisenberg Professor of Translational Medical Ethics at the University of Heidelberg and heads the research focus "Ethics and Patient Orientation" at the National Centre for Tumour Diseases. She is an oncology senior physician at the NCT, spokesperson of the EURAT group on ethical and legal questions of genome sequencing and, as one of the directors of GHGA, responsible for ethical aspects of the German Human Genome Phenome Archive.

Participants

Mr Rudolf Hauke

Chairman of the Patient Advisory Board for Cancer Research at the DKFZ

Rudolf Hauke was born and grew up in Augsburg. In 1999 he was elected to the board of directors of the Kaufmännische Krankenkasse in Hanover, where he worked until 2015. Since 2002, he has been involved with the Association for Children with Cancer in Hanover and since 2018 he has been chairing the first patient advisory board at the German Cancer Research Centre (DKFZ). His first book "Der fremde Tropfen in meinem Blut" (The foreign drop in my blood), an autobiographical story about cancer therapy, was published at the end of 2015. His second book, an emotional story about "Nursing care assessment - how human fates are set in guidelines", will be published at the end of the year.

Dr. Christine Mundlos

Deputy managing director for the Alliance of Chronic Rare Diseases (ACHSE)

After studying medicine in Mainz in the early 1990s, Christine Mundlos first worked in laboratory medicine (human genetic diagnostics) and later in molecular genetics (research). Since 2000 she has lived with her family near Berlin, where she completed a Master's degree in "Science Marketing and Science Communication" at the TU from 2005 to 2007. Since the end of 2008 she has been working as a medical assistant and in the meantime as deputy managing director for the Alliance of Chronic Rare Diseases (ACHSE) e.V. at the interface between medicine and research.

Dr. Stefanie Houwaart

Coordinator of the advisory board of the BRCA Network - Help with Familial Breast and Ovarian Cancer

Dr. Stefanie Houwaart grew up with hereditary cancer and, as a family member and high-risk patient, has been sensitised to the complex circumstances and consequences of cancer. She studied biology and since 2012 she has been involved in cancer self-help on a voluntary basis, especially in patient advocacy. Since November 2020 she has been working in the German Cancer Aid for the coordination of patient interests.

Ms Bärbel Söhlke

Co-founder of "zielGENau e. V.", a nationwide non-profit patient network for personalised lung cancer therapy

Frau Bärbel Söhlke is Co-founder of the German "ROS1ders" as part of a worldwide oncogene-focused patient network. In 2020 co-founder of "zielGENau e. V.". (www.zielgenau.org), a nationwide non-profit patient network for personalised lung cancer therapy. As a patient representative, she is committed to ensuring that these advances reach as many patients as possible and are intensively promoted.

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Closing remarks by the German Federal Ministry of Health

Ms Dagmar Friese

Head of Division “Biotechnological Innovation, Nanotechnology and Genetic Engineering” of the German Health Ministry

Dagmar Friese, Pharmacist, Studies in Experimental Pharmacology and Toxicology; previously worked as scientist in cancer research in the field of chemical carcinogenesis; until 2001 employed as scientific officer in regulatory affairs at the Federal Institute of Drug and Medical Devices (BfArM); joined the German Health Ministry in 2001 and before taking a leading position in the ministry worked as consultant at the Permanent Representation of Germany to the EU (2006) and as seconded national expert at the European Commission, DG Research, until 2008.

Since 2009 Head of Division “Biotechnological Innovation, Nanotechnology and Genetic Engineering”; present responsibilities are general affairs in innovative biotechnology and issues of biopharmaceuticals, including advanced therapy medicinal products, questions of principle in life sciences, of genetic engineering and nanotechnology of importance for the process of drug discovery and development.

Closing remarks by the European Commission

Dr. Christoph Schwierz

Head of Unit 'Labour Market, Health and Social Services' in the Directorate General for Structural Reform Support (DG REFORM) of the European Commission

Christoph Schwierz, Dr. rer. pol. (PhD Economics), is currently Acting Head of Unit 'Labour Market, Health and Social Services' in the Directorate General for Structural Reform Support (DG REFORM) of the European Commission, where he is facilitating technical support to EU countries for structural reforms in the labour market, education, health & social services sectors; he previously worked on assessing the fiscal sustainability of health systems in the Directorate General for Economic and Financial Affairs of the European Commission; In the past, he did research on health economics in the Belgian Health Care Knowledge Center, the Rhine-Westphalian Research Institute for Economic Research in Germany, Health Economics Bergen in Norway and the Netherlands Interdisciplinary Demographic Institute in The Hague. He has published in Health Economics and other peer-reviewed journals.

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