Next Generation Medicine?

Ethical, Legal and Technological Questions of Genomic High-Throughput Sequencing in the Clinic

Date July 25 (start at 12:00) / July 26 2017 (16:00 end of meeting)

Venue

University Medical Center Goettingen, Lecture Hall MED 25 Von-Siebold-Straße 3, 37075 Goettingen

Organized by

the GenoPerspektiv Consortium Ulrich Sax, PhD, Nadine Umbach, PhD, Department for Medical Informatics, University Medical Center Goettingen

Due to increasingly effective technological platforms, sequencing of the human genome is now possible within hours and for less than 1.000 Euro. This development has sparked growing interest among clinicians and molecular biologists. The aim is to target rare, clinically unrecognizable diseases or to subtype clinically indistinguishable disorders with a suspected genetic background, e.g., in the oncological context. More and more clinicians, patients, and stakeholders are becoming aware of the possibilities of biomarker-based high-throughput analyses. Genomic high-throughput technologies are frequently hailed as a revolutionary tool that will radically change clinical practice and establish "predictive", "individualized" or "precision" medicine.

At the same time, the clinical implementation of the rapid technological advances in the field of genomic high-throughput sequencing is accompanied by practical difficulties and uncertainties. The interpretation and reporting of genomic findings in clinical practice, e.g., in molecular tumor boards, becomes more complicated, challenging the traditional roles and qualifications of medical professionals. The increasing volume of huge and highly complex data sets also poses problems regarding sustainable infrastructures for management, integration and exploration of genomic sequencing data with other clinical data. And finally, the large pool of sensitive and ambiguous data raises ethical, legal, and social questions that are still in need of clarification, especially regarding informed consent, disclosure policies, and data protection: How can we protect patient autonomy and informational self-determination in view of huge amounts of genomic information with unclear clinical significance and future usage? What kinds of genomic information should be disclosed to patients and in what way? And how should we deal with so called incidental findings, that is, originally unintended information about a person's genetic predispositions and medical conditions?

The international workshop brings together experts from the fields of medicine, ethics, social sciences, law, and biomedical informatics as well as the public. The aim is an interdisciplinary

discussion of the opportunities and challenges posed by clinical applications of genomic high-throughput sequencing.

Confirmed speakers include:

<u>Dr. Leslie G. Biesecker</u>, National Human Genome Research Institute, NIH, Head of Clinical Genomics Sections (keynote lecture)

<u>Dr. Jürgen Eils</u>, German Cancer Research Center and Heidelberg University, Head of Data Management and Genomics IT

<u>Prof. Dr. Ernst Hauck</u>, Presiding Judge at the Federal Social Court, Kassel

<u>Dr. Dennis-Kenji Kipker</u>, University of Bremen, Research Managing Director of the Institute for Information, Health and Medical Law

<u>Prof. Dr. Christophe Le Tourneau</u>, Institut Curie, Paris, Department of Medical Oncology, Head of Early Phase Clinical Trials

<u>PD Dr. Peter Wehling.</u> Goethe University Frankfurt am Main, Faculty of Social Sciences, Institute of Sociology

Poster session

<u>We invite the submission of abstracts</u> that report new research developments across the breadth of clinical genomic, precision medicine, next-generation sequencing, biomarker analysis, reporting or related ethical, social, legal, and bioinformatical issues. Abstracts are considered for a <u>poster</u> <u>presentation and an oral presentation</u>. Submissions are welcomed from physicians, researchers, PhDs, and students in all sectors, including academia, industry, and education.

Abstracts are limited to 500 words and should be divided in introduction, materials & methods, results, and discussion. German and English contributions are accepted.

<u>Abstract submission will be open to June 25, 2017,11:59 PM MEZ: genoperspektiv@med.uni-goettingen.de</u>

Registration / further questions:

Please send a mail to: genoperspektiv@med.uni-goettingen.de

Participation is free of charge.