



## Public health genomics in Europe

### The challenge of integrating genomics into public health

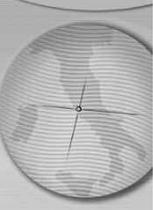
The Human Genome Project was completed in 2003. Expectations are high that new knowledge and technologies arising from the project will soon contribute to the improvement of individual and population health. Yet, approaches in public health have so far not broadly used molecular knowledge of individual genetic susceptibility for achieving their goals. However, in the past decade there has been increasing awareness that advances in genomics can be utilised in public health in the near future. It is our opinion that it is of major importance to start discussion of this option and its possible consequences early enough. This thematic issue starts from the premise that public health approaches can and should no longer ignore the advances made in genomics. We are seeing the emergence of the multidisciplinary field of public health genomics that deals with these opportunities and challenges. According to the statements of an expert group that discussed public health genomics concepts in Bellagio in 2005, public health genomics can be defined as: "The responsible and effective translation of genome-based knowledge and technologies for the benefit of population health (Bellagio Report)."

### The Public Health Genomics European Network (PHGEN): approach and tasks

Being aware of future possible benefits of genomics in population health, in 2005 the European Commission made a call in the programme "community action in the field of public health" for a networking exercise. The networking exercise would identify "public health issues linked to current national practices in applying genetic testing and on that basis contributes to developing best practice in applying genetic testing." The Institute of Public Health North Rhine-Westphalia (Iögd) in Bielefeld, Germany, as leading partner together with the Public Health Genetics Unit (PHGU) in Cambridge, UK, and the German Center for Public Health Genomics (DZPHG) at the University of Applied Sciences in Bielefeld, Germany, applied for PHGEN and received the funding.

PHGEN involves experts as collaborating partners from the fields of public health and epidemiology, human genetics and molecular biology, social sciences, ethics, medicine, economics, political sciences and law. These experts cover all EU member states, applicant countries and EFTA-EEA countries. Representatives of other European networks (e.g. EuroGentest, Orphanet, EUnetHTA, PHOEBE or NuGO) are involved and delegates of relevant initiatives and institutions on the European and international level such as WHO, WTO, OECD, STOA, AETMIS, National Office of Public Health Genomics (USA), GRaPH Int, HumGen, TOGEN or UK DNA Banking Network are invited to participate to ensure complementary work and promote synergies in achieving the Network's goals. Among the goals are: to accomplish an inventory of issues and priorities related to public health genomics in Europe; to identify legal diversities and barriers in a cross-border market; and to analyse the relevance of EU treaties for public health genomics. A derivative of this networking is a directory of key experts and institutions relevant to public health genomics in PHGEN member countries. It is envisaged that PHGEN together with its spin-offs will serve the European Commission as an "early detection unit" for horizon scanning, fact finding, and monitoring of the integration of genome-based knowledge and technologies into public health.

The steering group of PHGEN has developed the concept of "PHGEN National Task Forces" to promote and stimulate efforts in PHGEN member countries for



effective networking in order to reach sustainability of discourse and institutionalisations in the countries. Furthermore, these “PHGEN National Task Forces” discuss and explore the situation in their countries, develop suggestions for national strategies and report results back to the PHGEN hub.

#### **The PHGEN Bielefeld Conference 2006**

The “Public Health Genomics European Network (PHGEN)” officially started in the 2006. Its members convened for the first time from February 8<sup>th</sup> until 9<sup>th</sup> 2006 in the Centre for Interdisciplinary Research (ZiF) in Bielefeld, Germany, where the first international conference on Public Health Genomics had already taken place in February 2004. The initial PHGEN meeting was conducted under the heading “Assessing Issues and Priorities of Public Health Genomics.” Apart from the aim of this meeting to give members and observers of PHGEN the possibility to get to know each other and the topic of Public Health Genomics, first steps were taken in the direction of discussing what issues and priorities would be encountered in the European Union and affiliated countries when integrating genome-based knowledge into population health.

#### **Papers in this issue**

This issue contains the basic topics and discussion results from the Bielefeld conference in February 2006.<sup>1</sup> In a first more general part of this issue on “Public Health Genomics”, Ron Zimmern and Alison Stewart describe the scope of the ‘enterprise’ of public health genomics as discussed in the Bellagio Report. When laying out issues and priorities of public health genomics, they also touch upon the thesis of “genetic exceptionalism” which Peter Schröder further explores in his contribution. Dolores Ibarreta and Line Matthiessen-Guyader discuss European activities towards improving the quality of genetic testing from the perspective of the European Commission (DG Research).

In the second section on “Assessing Issues and Priorities of Public Health Genomics”, Angela Brand and Helmut Brand more broadly describe the opportunities and challenges of public health genomics. They describe in detail the tasks and approach taken by the “Public Health Genomics European Network (PHGEN)”. Cecile Janssen and Muin Khoury argue that genomic profiling for complex diseases is more similar to non-genetic tests than to predictive tests for monogenetic diseases. To accomplish a truly individualized medical approach, Alexander Trbovic states that it is a task of public health genomics to create an effective modus for the coexistence of new molecular discoveries and classical medical techniques. Tobias Schulte in den Bäumen discusses ethical and legal benchmarks of governance in genomics.

A Glossary defines public health genomics relevant terms. Finally, in the letters sections, Serdar Savas reports from the Turkish and Stefania Boccia and Walter Ricciardi report from the Italian PHGEN National Task Force. These were the first PHGEN National Task Forces to meet and will provide valuable experience for the upcoming PHGEN National Task Forces.

#### **Acknowledgements**

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<sup>1</sup>A documentation of the meeting (incl. slides of the presentations and minutes) can be found on the website of PHGEN ([www.phgen.eu](http://www.phgen.eu)).