



## Genom Austria launches as a new member of the Personal Genome Project

### A project to explore the impact of genome sequencing on science and society

*(Vienna, 25 November 2014) Breakthrough sequencing technology makes it possible to analyze human genomes at relatively low cost. 'Genom Austria' is a joint project of the PersonalGenomes.org foundation, the CeMM Research Center for Molecular Medicine of the Austrian Academy of Sciences, and the Medical University of Vienna. It explores the scientific, educational, ethical, and social implications of personal genome sequencing. Following the model of Harvard's Personal Genome Project, 'Genom Austria' provides qualifying volunteers the opportunity to sequence their personal genomes and to share the data with the public.*

In many countries, genome sequencing technology is now starting to become available in the clinic, where it helps to diagnose rare Mendelian diseases and contributes to personalized cancer therapy. The analysis of personal genomes also creates unprecedented opportunities for predictive health counseling, ancestry research, and many more applications that are just starting to emerge.

Despite the strong impact that personal genome sequencing is likely to have in healthcare and beyond, public discussions on the societal and ethical aspects of this technology are only starting in most countries. *Genom Austria* thus aims to create a forum for such discussions at the interface of science and society.

To make personal genome sequencing concrete and tangible for people in Austria, the project will provide interested volunteers with the opportunity to have their genomes sequenced with state-of-the-art technology and to share the data with the public.

Participation is entirely voluntary and restricted to individuals who demonstrate adequate understanding of the implications of making their personal genomes publicly available. In its initial phase in 2015, *Genom Austria* will sequence the personal genomes of 20 selected volunteers who have consented to publish their genomes and related information openly and freely on the Internet.

*Genom Austria* will also contribute to science education by organizing a school project and open science workshops. Furthermore, it creates a forum for interdisciplinary dialog among experts and the general public in areas such as biology, medicine, ethics, sociology, psychology, history, and the arts.

Internationally, *Genom Austria* builds upon the pioneering work of the Personal Genome Project at Harvard, which was initiated by George Church in 2005 and currently has over 3,000 participants. *Genom Austria* is a member of the Global Network of Personal Genome Projects. It also collaborates with other member sites in the USA, Canada, and the UK, in order to exchange best practices in personal genomics, open science, participatory research, and engagement with society.

*Genom Austria* is physically based at the CeMM Research Center for Molecular Medicine of the Austrian Academy of Sciences in Vienna and jointly run with the Medical University of Vienna.



### **PersonalGenomes.org and the Global Network of Personal Genome Projects – brief profile**

PersonalGenomes.org is a charitable organization working to generate, aggregate and interpret human biological and trait data on an unprecedented scale. Our mission is to make a wide spectrum of data about humans accessible to increase biological literacy and improve human health. PersonalGenomes.org's programs are informed by values encouraging greater transparency and collaboration between researchers and the public. The organization coordinates the Global Network of Personal Genome Projects, with member sites at leading institutions in four countries. Other groundbreaking programs include Open Humans and the annual Genomes, Environments and Traits (GET) Conference. For further information, please visit: [www.personalgenomes.org](http://www.personalgenomes.org).

### **CeMM Research Center for Molecular Medicine of the Austrian Academy of Sciences – brief profile**

CeMM is an international, independent, and interdisciplinary research institute for molecular medicine. "From the clinic for the clinic" – CeMM is guided by medical needs, and it integrates fundamental research with clinical expertise in order to develop innovative diagnostic and therapeutic approaches. Its research projects focus on cancer as well as on inflammatory and immunological disorders. For further information, please visit [www.cemm.oeaw.ac.at](http://www.cemm.oeaw.ac.at).

### **Medical University of Vienna (MedUni Wien) – brief profile**

The Medical University of Vienna is one of the longest-established medical training and research institutions in Europe. With almost 7,500 students, it is today the largest medical training body in the German-speaking world. With its 27 university hospitals, 12 medical research centers and many highly specialized laboratories, it is also among the most important cutting-edge biomedical research centers in Europe. For further information, please visit [www.meduniwien.ac.at](http://www.meduniwien.ac.at).

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Austrian website: <http://genomaustria.at> (in German only)

International website: <http://personalgenomes.org/austria> (English & German)



### **Voices about the launch of Genom Austria as a new member of the Personal Genome Project:**

*"We have a tremendous amount to learn yet about the connections between our genomes, environments and traits. Collaboration between citizens and researchers is essential to realizing the potential benefits of genome sequencing. Genom Austria and the other members of the Global Network of Personal Genome Projects serve as a valuable forum for catalyzing these developments."*

Jason Bobe, Citizen Science Expert & Executive Director of PersonalGenomes.org

*"Personal genomes will be commonplace just a few years from now. They will profoundly change medicine and could also affect many other parts of our lives. Society is unprepared for this genomic future. Genom Austria, as a new member of the Global Network of Personal Genome Projects, will stimulate an open discussion about how to shape our genomic future in the interest of everybody. It will also contribute to a global resource of personal genomes that is non-commercial and open to all."*

Christoph Bock, Genome Scientist & Project Leader Genom Austria

*"People join a Personal Genome Project to help and be helped. Or to share their genetic superpower. We are not providing a service and these are early days, but still people learn useful news. Like one who found a JAK2 clotting mutation and now takes aspirin daily. Personal Genome Project volunteers are so engaged in trait data collections. This level of participatory medicine is amazing, inspiring."*

George Church, Geneticist & Founder of Harvard's Personal Genome Project and PersonalGenomes.org

*"It was an exciting experience to sequence my personal genome as part of Genom Austria. You hope for some surprise. But if you roughly know where you come from and the health history of the parents and grandparents, there's not too much that would come entirely unexpected. For example, I'm a heterozygous carrier of beta-thalassemia or Mediterranean anemia, which is historically related to malaria in the region where I was born. A 'gift' from other times and places that makes me look a bit pale and less likely to be an outstanding endurance athlete. But these are details. The overall feeling was joy, feeling unique and decoded as an individual."*

Giulio Superti-Furga, Molecular Biologist & Chairman of Steering Board & Scientific Director of CeMM