

## The Study of Estonian Human Genes Database

### I. Introduction

The human genes database or human genome project, the product under the policy of biotechnology no matter in a developed or developing country, has been paid more attention by a government and an ordinary people gradually. The construction of human genes database or human genome project, which is not only related to a country's innovation on biotechnology, but also concerns the promotion of a country's medical quality, the construction of medical care system, and the advantages brought by the usage of bio-information stored in human genes database or from human genome project. However, even though every country has a high interest in setting up human genes database or performing human genome project, the issues concerning the purposes of related biotechnology policies, the distribution of advantages and risks and the management of bio-information, since each country has different recognition upon human genes database or human genome project and has varied standards of protecting human basic rights, there would be a totally difference upon planning biotechnology policies or forming the related systems. Right now, the countries that vigorously discuss human genes database or practice human genome project include England, Iceland, Norway, Sweden, Latvia and Estonia.

Estonia, which is the country around the Baltic Sea, has planned to set up its own human genes database in order to draw attention from other advanced countries, to attract intelligent international researchers or research groups, and to be in the lead in the area of biotechnology. To sum up, the purpose of constructing Estonian human genes database was to collect the genes and health information of nearly 70% Estonia's population and to encourage bio-research and promote medical quality.

### II. The Origin of Estonian Human Genes Database

The construction of Estonian human genes database started from Estonian Genome Project (EGP). This project was advocated by the professor of biotechnology Andres Metspalu at Tartu University in Estonia, and he proposed the idea of setting up Estonian human genes database in 1999. The purposes of EGP not only tried to make the economy of Estonia shift from low-cost manufacturing and heavy industry to an advanced technological economy, but also attempted to draw other countries' attention and to increase the opportunity of making international bio-researches, and then promoted the development of biotechnology and assisted in building the system of medical care in Estonia.

EGP started from the agreement made between Estonian government and Eesti Geenikeskus (Estonian Genome Foundation) in March, 1999. Estonian Genome Foundation was a non-profit organization formed by Estonian scientists, doctors and politicians, and its original purposes were to support genes researches, assist in proceeding any project of biotechnology and to set up EGP. The original goals of constructing EGP were "(a) reaching a new level in health care, reduction of costs, and more effective health care, (b) improving knowledge of individuals, genotype-based risk assessment and preventive medicine, and helping the next generation, (c) increasing competitiveness of Estonia – developing infrastructure, investments into high-technology, well-paid jobs, and science intensive products and services, (d) [constructing] better management of health databases (phenotype/genotype database), (e) ... [supporting]... economic development through improving gene technology that opens cooperation possibilities and creates synergy between different fields (e.g., gene technology, IT, agriculture, health care)"<sup>1</sup>.

### III. The Way of Constructing Estonian Human Genes Database

In order to ensure that Estonian human genes database could be operated properly and reasonably in the perspectives of law, ethics and society in Estonia, the Estonian parliament followed the step of Iceland to enact "Human Genes Research Act" (HGRA) via a special legislative process to regulate its human genes database in 2000. HGRA not only authorizes the chief processor to manage Estonian human genes database, but also regulates the issues with regard to the procedure of donation, the maintenance and building of human genes database, the organization of making researches, the confidential identity of donator or patient, the discrimination of genes, and so on.

Since the construction of Estonian human genes database might bring the conflicts of different points of view upon the database in Estonia, in order to "avoid fragmentation of societal solidarity and ensure public acceptability and respectability"<sup>2</sup>, HGRA adopted international standards regulating a genes research to be a norm of maintaining and building the database. Those standards include UNESCO Universal Declaration on the Human Genome and Human Rights (1997) and the Council of Europe's Convention on Human Rights and Biomedicine (1997).

The purpose of enacting HGRA is mainly to encourage and promote genes researches in Estonia via building Estonian human genes database. By means of utilizing the bio-information stored in the database, it can generate "more exact and efficient drug development, new diagnostic tests, improved individualized treatment and determination of risks of the development of a disease in the future"<sup>3</sup>. In order to achieve the above objectives, HGRA primarily puts emphasis on several aspects. Those aspects include providing stronger

protection on confidential identity of donators or patients, caring for their privacy, ensuring their autonomy to make donations, and avoiding any possibility that discrimination may happen because of the disclosure of donators' or patients' genes information.

1.HERBERT GOTTWEIS & ALAN PETERSEN, BIOBANKS – GOVERNANCE IN COMPARATIVE PERSPECTIVE 59 (2008).

2.Andres Rannamae, Populations and Genetics – Legal and Socio-Ethical Perspectives, in Estonian Genome Project – Large Scale Health Status Description and DNA Collection 18, 21 (Bartha Maria Knoppers et al. eds., 2003.

3.REMIGIUS N. NWABUEZE, BIOTECHNOLOGY AND THE CHALLENGE OF PROPERTY – PROPERTY RIGHTS IN DEAD BODIES, BODY PARTS, AND GENETIC INFORMATION, 163 (2007).

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