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***Joint statement calling for legislation to prevent discrimination and social disadvantage due to genetic and genomic information.***

Genomic medicine is based on an individual's genetic and genomic information and is used to optimize treatment, predict the development and prevent the onset of cancer and other intractable diseases. Advances in genomic medicine can bring new hope to many patients through personalized medicine (precision medicine), including ones with intractable and rare diseases.

In the case of cancer, there are two types of genetic mutations that may cause its onset: germline mutations (genetic mutations inherited from parents) and somatic mutations (acquired genetic mutations that occur after birth). As genomic medicine and research progress, it is possible that "cancer patients with hereditary tumours" and "patients with new gene mutations" will be identified in the course of testing and treatment. In addition, the Whole Genome Analysis Project, which is also underway in Japan, may lead to new knowledge about the risk of developing various diseases, not only for patients who have already developed cancer or intractable diseases, but also for those who are asymptomatic and are currently considered to be healthy.

In the U.S., the *Genetic Information Nondiscrimination Act* (GINA) of 2008, which regulates the use of genetic information in employment and insurance, prohibits the use of genetic information in the hiring, promotion, and dismissal of employees, and prohibits insurance companies from limiting insurance coverage or adjusting premiums based on genetic information. In the U.K., there are also regulations in employment and an agreement between the government and the Association of British Insurers (ABI) for insurance. There are no such laws or regulations in Japan, despite the promotion of genomic medicine.

In December 2018, the Japan Federation of Cancer Patient Groups submitted a written request to the Senior Vice-Minister of Health, Labour and Welfare, Yoshinori Oguchi, calling for legislation and regulations to appropriately promote genomic medicine and protect patients and others from social disadvantage. The Genetic Alliance JP has also submitted the request to the relevant ministries and parliamentarians since 2017 to urge the Government of Japan to promptly enact laws and regulations in Japan to ensure that 'patients with genetic diseases' and 'unaffected persons with genetic mutations' do not suffer discrimination or social disadvantage due to the acquisition of genetic information or its inappropriate handling in employment and insurance.

The government's "Basic Policies for Economic and Fiscal Management and Reform 2019" states that "in promoting genomic medicine, necessary measures should be taken to create a society in which citizens are not disadvantaged by genomic and genetic information". In addition, the "Whole Genome Analysis Action Plan (1st edition)" states "it is important to improve the social environment by ensuring consultation and support programs and disseminating knowledge and educating about genome research and medical care so that no one is treated inappropriately or disadvantaged in any situation, by the results of whole genome analysis, and other related information". In Japan, there are currently no laws or self-regulations regarding the prevention of discrimination and social disadvantages.

On April 6, 2022, the Japanese Association of Medical Sciences, the Japanese Medical Science Federation and the Japan Medical Association released a "Joint Statement on the Prevention of Unfair Discrimination and Social Disadvantage due to Genetic and Genomic Information," calling for the "urgent implementation of legal measures to prevent unjust discrimination and social disadvantage based on genetic and genomic information". The Japan Federation of Cancer Patient Groups and the Genetic Alliance JP strongly support this joint statement and reiterate the following requests to the government:

- The Government of Japan should urgently implement legislation and regulations to prevent discrimination and social disadvantage due to personal genetic and genomic information.
- Relevant ministries and agencies should take measures to prevent discrimination and social disadvantage due to the acquisition of genetic information and its inappropriate handling in the employment and insurance sectors, etc. They should additionally consider effective measures to ensure that no social disadvantage is caused.
- The establishment of a policy framework to resolve ethical, legal and social issues related to genomic medicine.

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We would like to acknowledge the following contributors to the translation:

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The original can be found at:

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