

**Commentary**

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**Necessity of cooperation with government on publication of scientific research results for intractable diseases**Yoshinori Inagaki<sup>1,2,\*</sup>, Peipei Song<sup>2</sup><sup>1</sup>Laboratory of Microbiology, Graduate School of Pharmaceutical Sciences, The University of Tokyo, Tokyo, Japan;<sup>2</sup>Hepato-Biliary-Pancreatic Surgery Division, Department of Surgery, Graduate School of Medicine, The University of Tokyo, Tokyo, Japan.**Summary**

The features of intractable diseases make it an important public health issue and a challenge to medical care worldwide. Investigation of intractable diseases with the support of government is urgently expected to activate clinical and pharmaceutical research to promote diagnosis and treatment for patients with intractable diseases. Moreover, linkage to the international database for research achievement is also necessary so that both researchers and other general citizens can assess research trends in the field of intractable diseases. In Japan, supportive activities for patients and researchers of intractable diseases have been well developed with the support of the Ministry of Health, Labor and Welfare (MHLW). Furthermore, in April 2013, a specific academic communication platform on intractable diseases – the Intractable and Rare Diseases Research (IRDR) Journal – was approved to join a governmental project and receive support from the Japan Society for the Promotion of Science (JSPS) under the auspices of Ministry of Education, Culture, Sports, Science and Technology (MEXT). Cooperation with the Japanese government starting this year is hoped to promote information-sharing based on an academic communication platform and further activate research on intractable diseases.

**Keywords:** Intractable diseases, rare diseases, orphan drugs, governmental supports

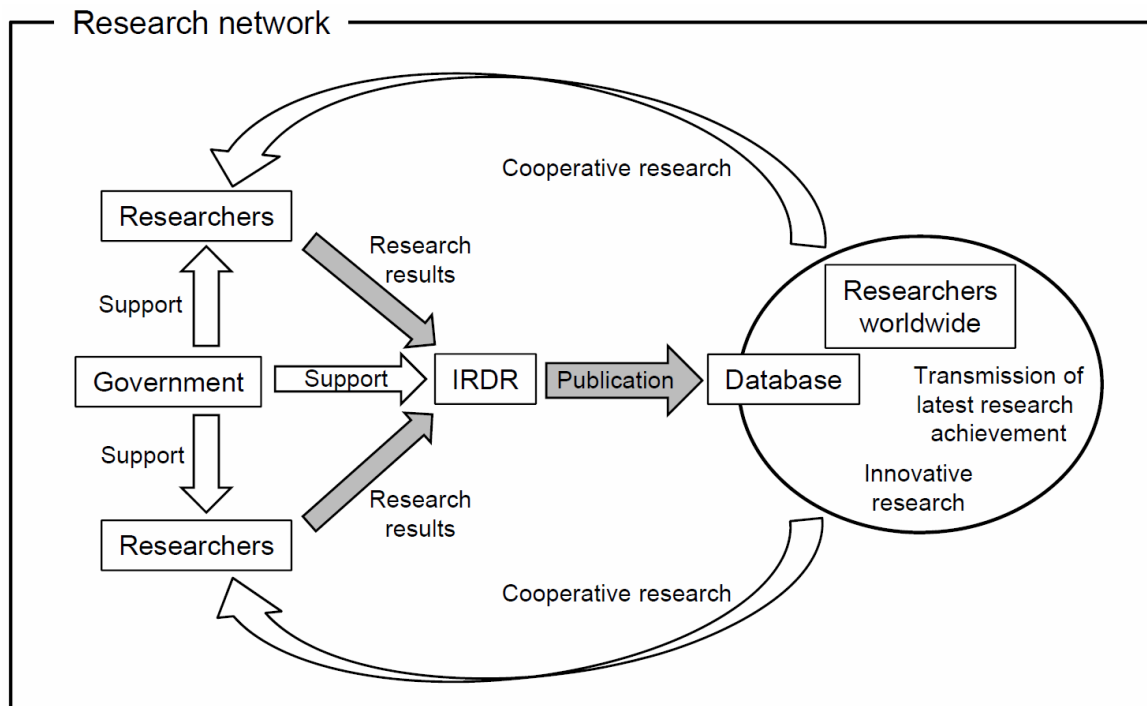
There are many patients suffering from intractable diseases worldwide which have an uncertain etiology, no effective therapeutic methods, and heavy burdens on not only patients but also other family members financially and mentally. Several countries such as the United States, European and some Asian countries deploy various efforts for the purpose of medical and financial rescue for those patients (1). Most intractable diseases are chronic diseases, therefore continuous financial support from government is essential for patients. On the other hand, financial supports have also been provided to investigations regarding intractable diseases. Those supports contribute to activate clinical and pharmaceutical research to survey the patients'

prognosis and develop effective orphan drugs (2). Newly-developed technologies are actively applied. Development of current life science technology such as genomic analysis using next-generation sequencing and regenerative medicine using induced pluripotent stem (iPS) cells contributes to the understanding of pathogenetic mechanisms and establishment of new diagnostic or therapeutic strategies (3,4). However, progression of this research takes a fair amount of time because each disease has characteristic pathogenic mechanisms and some of the diseases, called "rare diseases", have a fewer number of patients. Thus, a long-term continuous effort of support for research is also necessary for academic research.

Supportive activities for patients and researchers of intractable diseases are also deployed in Japan. The Ministry of Health, Labor and Welfare (MHLW) mainly administers those activities; epidemiological investigation regarding the current state of intractable diseases in Japan, provision of proper medical care and its financial support for patients, administration

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**Figure 1. Government-supported academic communication platform for publication of scientific research results for intractable diseases.** IRDR receives financial support from Japanese government and contributes to create a cooperative research network in the field of intractable diseases.

and supports of innovative academic research. Japan Intractable Diseases Information Center (JIDIC) was established by the cooperative enterprise of MHLW and the Japan Intractable Diseases Research Foundation for the purpose of disclosure of information about intractable diseases mainly in Japan. The website of JIDIC provides information on *i*) intractable diseases (130 diseases which MHLW approved as "Nanbyo"), *ii*) domestic researchers studying intractable diseases, and *iii*) medical welfare system for patients with intractable diseases. The number of accesses to this website is currently over 15 million per year, and therefore this website becomes significant to understand the present state of each intractable disease in Japan. However the description of the latest research achievements in foreign countries is inadequate on this website. Linkage to the international database for research achievements is required so that both researchers and other general citizens can assess the research trends in the field of intractable diseases. Information-sharing and implementation of cooperative work among domestic and foreign researchers are considered necessary to overcome each intractable disease as early as possible.

International Research and Cooperation Association for Bio & Socio-Sciences Advancement (IRCA-BSSA) group promotes cooperation in the field of intractable and rare diseases research *via* publication of the present journal "Intractable and Rare Diseases Research (IRDR)". This journal consolidates significant research achievements regarding intractable and rare diseases scattered in various academic fields and introduces

the latest results aggressively. In addition, a database summarizing individual proposed research plans is being constructed to activate intercommunication between researchers. This project leads information-sharing and implementation of cooperative work among researchers. Activation of the research field of intractable and rare diseases is expected to contribute to overcoming those diseases. Last April, the present journal, IRDR, was approved to join a governmental project and receive support from Japan Society for the Promotion of Science (JSPS) under the auspices of Ministry of Education, Culture, Sports, Science and Technology (MEXT). The purpose of this project, named "Grant-in-Aid for Publication of Scientific Research Results", is to construct a system that can transmit the limited research results to an international network. In Japan, until now, there has been no project constructing an international system regarding consolidation and transmission of research achievements regarding intractable and rare diseases with a financial support from government; furthermore, there is no journal like IRDR that focuses on the topics of intractable and rare diseases. In this journal, novel and significant research results are actively published and rapidly transmitted worldwide *via* internationally influential databases. The governmental support is essential to execute those plans (Figure 1). Cooperation with government that started this year is hoped to elevate this journal to an internationally high-impact one and activate the research field of intractable and rare diseases.

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