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EFPIA Japan

**EFPIA Japan Publishes Results of Survey in Hemophilia Patients on Their Lifestyles and Impact of COVID-19 – over 50% of Patients Changed Medication within Past Five Years, Some Contributing to Increased Activity, over 80% of Adult Patients Have Concerns about Aging**

TOKYO – 23 December 2021 – EFPIA Japan today published the results of the survey in hemophilia patients on their lifestyles and impact of COVID-19 ([efpia.jp/english-bloodproducts\\_work/](https://efpia.jp/english-bloodproducts_work/))

Hemophilia is a disease that takes time to stop bleeding due to a lack of clotting factors, which are proteins in the blood that are necessary for blood to clot.<sup>1</sup> Although advances in therapeutic drugs and the widespread use of regular replacement therapy have enabled many patients to lead lives similar to those of healthy individuals, there are still patients who feel limited in their activities due to the risk of bleeding, and some who suffer from joint problems such as intra-articular bleeding.<sup>1</sup> Hemophilia is primarily a genetic condition, although about 30% of patients have no family history of the disease and it is believed to be caused by a genetic mutation in such patients.<sup>1</sup> Patients generally require treatment throughout their lives, and many patients who receive treatment regularly self-infuse therapeutics. In recent years, there have been innovations in hemophilia treatment, such as the ability to extend dosing intervals and the launch of subcutaneous injections in addition to intravenous injections. In this context, this survey was conducted to identify hemophilia patients' intentions regarding activity, concerns associated with aging, and the impact of COVID-19.

This survey was initiated by EFPIA Japan Blood Products Working Team and the operations were contracted to INTAGE HEALTHCARE CORPORATION. Survey questionnaires were hand-delivered to hemophilia A and B patients or their parents/caregivers through healthcare professionals who agreed to cooperate in the survey, and the completed questionnaires were collected by mail for analysis. The number of valid responses to the survey, which was compiled with the consent of the patients, was 92.

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<sup>1</sup> World Federation of Hemophilia. Accessed in October 2021.  
Available at: <https://elearning.wfh.org/elearning-centres/introduction-to-hemophilia/>

The survey revealed that over 50% of the patients had changed their medication within the past five years, and 14% of the adult patients reported that a change in medication had improved their activity. This confirms the case that therapeutic innovation is providing opportunities for new treatment options and contributing to increased activity. Changes in the patients' environment, such as enrollment in school and employment, were the most common factors influencing changes in patients' activity. In terms of future activity intentions, over 80% of the adult patients responded that they wanted to increase their activity level.

Further, as the life expectancy in hemophilia patients increases due to improved treatment, the survey revealed that 83% of the adult patients were concerned about aging. In particular, anxiety about "difficulty in moving joints" was the most common concern as a potential issue associated with aging, and was also the topic that they most want to learn about in relation to aging, suggesting the importance of providing information about joint care in hemophilia treatment.

In terms of the impact of COVID-19, the most frequently cited concern was the risk of infection due to the use of public transportation and medical institutions during hospital visits. In addition, while 36% of the adult patients were willing to receive telemedicine, only 4% of the patients had experienced telemedicine. Because hemophilia treatment requires regular hospital visits, and because many patients have joint problems, the use and combination of telemedicine may be beneficial to hemophilia patients.

In EFPIA Japan, five companies (in alphabetical order) - Bayer Yakuhin, Chugai Pharmaceutical, CSL Behring, Novo Nordisk Pharma and Sanofi - provide hemophilia treatments in Japan, and their supply accounts for approximately 70%<sup>2</sup> of the Japanese market. On top of its commitment to the hemophilia community and further innovation in hemophilia treatment to address unmet patient needs, EFPIA Japan will reflect the results of the survey and promote initiatives that contribute to patients' active lifestyles and reducing anxiety associated with aging.

### **About Hemophilia**

Hemophilia is a condition in which bleeding takes a long time to stop due to a lack of clotting factors, proteins in the blood that are necessary for blood to clot.<sup>1</sup> It is estimated that 1 in 10,000 live births is affected by hemophilia.<sup>1</sup> Hemophilia is a genetic disease, but about 30% of cases

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<sup>2</sup> Calculated by summing the overall sales of hemophilia A, hemophilia B and hemophilia inhibitor treatments based on Encise Inc. sales data (January to December 2020).

have no family history and are said to be caused by genetic mutations.<sup>1</sup> There are two types of hemophilia: hemophilia A is caused by a deficiency of the coagulation factor factor VIII, and hemophilia B is caused by a deficiency or reduced function of factor IX.<sup>1</sup> In Japan, there are 5,410 hemophilia A patients and 1,186 hemophilia B patients.<sup>3</sup>

### **About EFPIA Japan Blood Products Working Team**

EFPIA Japan is an association representing European research-based pharmaceutical companies operating in Japan. The Blood Products Working Team promotes dialogues with government authorities and patient groups aiming to build a system to ensure a stable supply of medically essential plasma fractionated products and blood-related recombinant products based on the world's most advanced technology, and to contribute to a better life for patients.

### **About EFPIA Japan (<http://efpia.jp/>)**

Established in April 2002, EFPIA Japan represents 21 R&D-based European pharmaceutical companies operating in Japan. In 2020, combined sales from the member companies accounted for roughly 23% of the pharmaceutical market in Japan. The mission of EFPIA Japan is to “Contribute to healthcare and patients in Japan through the early introduction of innovative medicines and vaccines”. EFPIA Japan aims to strengthen dialogue with decision-makers in order to improve Japanese healthcare for all.

### **About EFPIA (European Federation of Pharmaceutical Industries and Associations)**

(<http://www.efpia.eu>)

EFPIA, EFPIA Japan's partner organisation, is headquartered in Brussels and represents the pharmaceutical industry operating in Europe. Through its direct membership of 36 national associations and 39 leading pharmaceutical companies, EFPIA provides the voice of companies committed to researching, developing and bringing new medicines to improve health and quality of life around the world.

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<sup>3</sup> Japan Foundation for AIDS Prevention. Commissioned project by Ministry of Health, Labour and Welfare. National survey of blood coagulopathy. Report 2019. Accessed in October 2021.  
[https://api-net.ifap.or.jp/image/data/blood/r01\\_research/r01\\_research.pdf](https://api-net.ifap.or.jp/image/data/blood/r01_research/r01_research.pdf)



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