



European Federation of Pharmaceutical
Industries and Associations

14 April 2020

EFPIA Japan

17 April is World Hemophilia Day EFPIA Japan is committed to supporting people with hemophilia

TOKYO—14 April 2020— 17 April is World Hemophilia Day. World Hemophilia Day was established in 1989 as an international awareness day for hemophilia and other bleeding disorders in commemoration of Frank Schnabel, founder of World Federation of Hemophilia. ¹ 17 April 2020 celebrates 30+ years of World Hemophilia Day.

Five member companies of EFPIA Japan, namely Bayer Yakuhin, Ltd, Chugai Pharmaceutical Co., Ltd., CSL Behring K.K., Novo Nordisk Pharma Ltd. and Sanofi K.K. (in alphabetical order) provide hemophilia treatment products in Japan and their supply accounts for roughly 70% of the hemophilia market in the country. ² Their research and development initiatives extend to new hemophilia treatment options, including non-blood clotting factors and gene therapy. In addition to the product supply and development, EFPIA Japan is committed to supporting people with hemophilia through individual member company efforts as well as cross-industrial initiatives as EFPIA Japan.

EFPIA Japan initiatives

EFPIA Japan Blood Products Working Team comprised of the five member companies supports people with hemophilia and other bleeding disorders through recommendations for effective utilization of raw blood plasma and ensuring a stable supply of blood products (1) and identifying the present state and issues that patients with hemophilia (2) and primary immune deficiency (3) face by conducting surveys in the patients. The collaboration among the companies enables EFPIA Japan to pursue cross-industrial initiatives that may not be achieved by individual companies.

(1) http://efpia.jp/link/EFPIA-J_Proposal_2nd%20Blood_Business_Committee_in_FY2018.pdf

(2) <http://efpia.jp/link/BIP2.pdf>

(3) http://efpia.jp/link/PID_J_180713_1.pdf

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Individual member company initiatives

Aid to patient associations and patient support organizations

The five member companies support hemophilia patients and their families through financial aid to National Hemophilia Network of Japan and Habataki Welfare Corporation and assistance to local patient group activities. At a global level, the companies support people with hemophilia in collaboration with World Federation of Hemophilia and European Haemophilia Consortium.

Product donation

In partnership with World Federation of Hemophilia and through an individual company foundation, the companies donate hemophilia treatment products and provide training for healthcare professionals to advance hemophilia care in developing countries with limited access to care.

Global Alliance for Progress

Global Alliance for Progress (GAP) is a humanitarian program launched on World Hemophilia Day April 2003 by World Federation of Hemophilia with the primary goal to greatly increase the diagnosis and treatment of people with hemophilia and other bleeding disorders.³ The companies support GAP through treatment product donation and financial aid. GAP brought about over 6.1 billion IUs cumulative increase in product supply and offered training to over 26,000 hemophilia treatment centers and healthcare professionals in developing countries.³

Hemophilia Foundation

Hemophilia Foundation was established in 2015 to improve access to quality care for people with hemophilia and allied bleeding disorders in developing and emerging countries.⁴ To date, the Foundation has helped diagnose over 27,000 people and train more than 43,000 healthcare professionals.⁴

Education and exchange programs through exercise and sports

Some people with hemophilia avoid exercise because they think it may cause bleeds.⁵ However, regular physical activity can help prevent bleeds and joint damage.⁵ Exercise is important for hemophilia patients as well for building healthy bones and strengthening the muscles that support joints.⁵ To promote hemophilia patient understanding about appropriate exercise and familiarize themselves with sports, the companies provide information about exercise suited for hemophilia patients and offer programs to experience sports, including table tennis, workout and futsal under the supervision of experts.



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- Changing Hemophilia:** <https://www.novonordisk.co.jp/sustainable/society/haemophilia.html>
- Hemophilia Navigator:** <https://csf-info.com/hemophilia-navi/dailylife/sports.html>
- Hemophilia Village:** <https://www.hemophilia.jp/ja/home/teacher/07/>
- Smile-On:** <https://smile-on.jp/sports.html>

Useful information for patients

The companies offer useful information for hemophilia patients depending on their age or life stage and life situation through websites and printing media. Information for carriers, patient families and school teachers is also available.

- Club Hemophilia:** <http://www.clubhaemophilia.jp/>
- Hemophilia Navigator:** <https://csf-info.com/hemophilia-navi/index.html>
- Hemophilia Today:** <https://www.hemophiliatoday.jp/>
- Hemophilia Village:** <https://www.hemophilia.jp/>
- Smile-On:** <https://smile-on.jp/>

Events and programs commemorating World Hemophilia Day

Hemophilia message contest:

https://www.hemophiliatoday.jp/common/images/pdf/message_contest2020.pdf

The hemophilia message contest solicits episodes associated with hemophilia from patients and their families to share thoughts of people who live positively with hemophilia and motivate patients to continue with treatment.

Dance content “Step by Step”:

<https://smile-on.jp/dance/dance1.html>

Dance exercise video developed under the supervision of a hemophilia rehabilitation specialist and a choreographer active in TV commercial choreography will be published online on 15 April. The video is geared primarily toward the first to 9th graders and guides them to dance to the music and enjoy exercise.

Hemophilia Lead:

<https://www.hemophilialead.net/#home>

Hemophilia Lead offers leadership training to develop leaders in patient support and advocacy for hemophilia and other bleeding disorders. The global program is aimed at people with hemophilia or a related bleeding disorder and those working in hemophilia advocacy across the globe. Japanese people with hemophilia have also participated in the program. The coming Hemophilia Lead will take place in June 2020.

Workout in Hemophilia Day:

<https://www.novonordisk.co.jp/sustainable/society/haemophilia.html>

Video contents showing how to do simple exercises at home were released. In addition, events that help solve questions about exercise and rehabilitation and workout together are organized. The next event will take place in October 2020.

About hemophilia

Hemophilia is a bleeding disorder where people with hemophilia can bleed for a longer time.⁶ Their blood does not have enough clotting factor, a protein in blood that controls bleeding.⁶ About 1 in 10,000 people are born with hemophilia.⁶ Hemophilia is usually inherited, while about 30% of people with hemophilia did not get it through their parent's genes.⁷ It was caused by a change in the person's own genes.⁷ In Japan, 5,410 people have hemophilia A and 1,186 people have hemophilia B.⁸

EFPIA Japan Blood Products Working Team

EFPIA Japan represents R&D-based European pharmaceutical companies operating in Japan. EFPIA Japan Blood Products Working Team pursues recommendations and dialogues with the Japanese Government and patient organizations aiming to contribute to better patient lives and to establish a stable supply process for medically essential plasma-derived products and recombinant products that are manufactured with world's most advanced technology.

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

Established in April 2002, EFPIA Japan represents 22 R&D-based European pharmaceutical companies operating in Japan. In 2018, 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



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companies committed to researching, developing and bringing new medicines to improve health and quality of life around the world.

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¹ World Hemophilia Foundation. Accessed in April 2020. <https://worldhemophiliaday.org/>

² Sum of sales of hemophilia A, hemophilia B and hemophilia inhibitor treatment products based on the pharmaceutical sales data in 2019 provided by Encise Inc.

³ World Hemophilia Foundation. Accessed in April 2020. <https://www.wfh.org/en/our-work-reg-national/gap-program>

⁴ Novo Nordisk Hemophilia Foundation. Accessed in April 2020. <https://nnhf.org/>

⁵ Kathy Mulder. Exercises for People with Hemophilia. World Federation of Hemophilia, 2006

⁶ World Federation of Hemophilia. Accessed in April 2020. https://elearning.wfh.org/elearning-centres/introduction-to-hemophilia/#what_is_hemophilia

⁷ World Federation of Hemophilia. Accessed in April 2020. https://elearning.wfh.org/elearning-centres/introduction-to-hemophilia/#how_do_you_get_hemophilia

⁸ Japan Foundation for AIDS Prevention. Ministry of Health, Labour and Welfare commissioned project. National Survey in Blood Clotting Disorders 2019. Accessed in April 2020. https://api-net.jfap.or.jp/image/data/blood/r01_research/r01_research.pdf