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2011
Annual Report

Korea Hemophilia Foundation

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한국혈우재단

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CONTENTS

At the time of the publication of the 2011 Annual Report, I would like to deeply appreciate a number of people who have made all efforts to improve the quality of life for the hemophilia patients in Korea and to help all activities of the Korea Hemophilia Foundation (KHF).

President's Message

The Annual Report of KHF has been published every year. It has especially been published in English to inform and to improve the environment of hemophilia in Korea and the activities of KHF at the opening year of the Conference of the World Hemophilia Federation. I believe that the hemophilia-related data reported in the Annual Report will be helpful for many hemophilia researchers to make their study plans and for government representatives to establish projects related to hemophilia.

As many of you already know, just 60 years ago, the Republic of Korea, which was in the vortex of war, was one of the poorest countries in the world. After three years of war ended, the entire country was devastated. But with efforts and passion for "let's live well", Korean people have now achieve the gool into the 15th largest economic power in the world. The hemophilia care environment has also been improved in similar way.

Until the 1980s, as all people were absorbed in only economic development, the support for hemophilia patients was insufficient. Although Green Cross Corp. produced an anti-hemophilic factor since May 1974, many patients were not able to use the factor concentrates due to the expensive price. Such a difficult environment has been slowly improved by the sympathetically sincere effort of hemophilia patients' mothers.

The mothers formed the Hemophilia Mothers Union in January 1985 and through their untiring government activities, public medical insurance coverage for hemophilia medical expenses could be raised to 80%. Finally, the Korean Society for Rehabilitation of Hemophilia Patients was established by hemophilia patients, their families and doctors on March 18, 1989.

However, even if public medical insurance pays for 80% of hemophilia medical expenses, the 20% paid by patients' families has become a heavy burden to general home economy. After hearing an emotional appeal from patients' mothers, the late Dr. Young-Sup, Huh, CEO of Green Cross Corp. made up his mind to establish the Korea Hemophilia Foundation (KHF) and finally, it was formed on February 11, 1991.

Thank to the foundation of KHF and its clinic and Green Cross Corp's dedicated sponsorship, patients could be supplied with factor concentrate expenses. Since then, hemophilia patients in Korea, for the first time, have been able to receive appropriate treatment.

Today, the treatment environment of hemophilia in Korea has reached a high level. Now the government's medical expenses support for rare and incurable disease patients makes reduces patient families' worries about medical cost. Also, KHF's 3 affiliated clinics and more than 10 hospitals across the country treat hemophilia patients. Through these medical facilities, one hemophilia patient uses 100,739.54 IU of hemophilia A and 75,062.68 IU of hemophilia B for a year in Korea.

In May last year, about 40 hemophilia care physicians and researchers joined 'Hemophilia Working Party' organized during the Korean Society of Hematology's spring symposium. I think that this can play a large role in the development of national hemophilia care and research.

As I mentioned previously, all of these developments would be impossible without the sympathetic and sincere efforts of hemophilia patients' mothers to rescue their children from the illness as well as the gracious sponsorship of the late Dr. Young-Sup Huh, who practiced compassionate corporate social contribution.

In the future, all staff members of KHF will never forget the efforts of patients' mothers and the late Dr. Young-Sup Huh's devotion to lay the foundation stone of today. The staff will continue to try their best to improve the quality of life for hemophilia patients.

I hope that more people can participate in these activities of KHF.

Thank you.

Tai Ju Hwang
President
Korea Hemophilia Foundation

Activities in 2011

Overview
Activities in 2011
KHF Clinics
Patients' Story

Overview

On February 11, 2011, the Korea Hemophilia Foundation (KHF) celebrated the 20th anniversary of the establishment.

With about 120 people in attendance, KHF held the 20th anniversary on April 15. Yong-Mook Choi, President, in his speech at the 20th anniversary of the establishment, said that over the past 20 years, the hemophilia care environment of our country has been rapidly developing and KHF's change and development is to keep pace with these changes in the environment.
He asked many people's participation and support while stressing our active help to overcome the difficult environment.

"I am deeply grateful to the late Dr. Young-Sup Huh of Green Cross Corp. for his the great contribution to dedicated caring of hemophilia patients and their families in Korea," Alison Street, Vice President of Medical of the World Federation of Hemophilia (WFH), attending on behalf of the WFH commended the achievements of the late Dr. Young-Sup Huh, founder of KHF, in a congratulatory speech. And she added while visiting KHF, she was greatly impressed by the foundation's staffs, its facilities, hemophilia patient care, particularly accessibility, availability, and registration of factor concentrates. She added that Korea has already achieved the world's top 10 level in protection of hemophilia patients.

During the ceremony, nine people who have improved the quality of life for hemophilia patients and contributed greatly to KHF's hemophilia activities received merit awards and an award ceremony for the essay competition winners conducted to commemorate the 20th anniversary of KHF followed.
In particular, when Young-Jung Kim, a hemophilia patient, recited "Do I Deserve Respect Instead of Pity?" which was selected as the best essay, all the hall was filled with reverential silence.

□ Merit Award Winners

△Myung-Chul Yoo (Vice President of Medical Department, Kyung Hee University)
△Tai Ju Hwang (Professor, Chonnam National University)
△Kun-Soo Lee (Professor, Kyungpook National

University)
△Hyung-Jun Kim (Professor, Chung-Ang University)
△Robert Leung (Program manager of Asia and West Pacific Region, The World Federation of Hemophilia)
△Deok-Hyun Yoo (Former President of Kohem Association)
△Young-Jin Jang (Director of KHF)
△Se-Jin Kwon (Chief Physical Therapist of KHF Clinic)
△Hey-Sook Noh (Head of Welfare Support Department, KHF Executive Office)

□ Hemophilia Patients' Story Competition Winners

△ **The best work :** "Do I Deserve Respect Instead of Pity?" by Young-Jung Kim (see on page 22)
△ **Excellent work:** 'Start' by Seung-Ho Lee
△ **Work of merit:** 'Pleasant shackles' by Seung-Eon You, 'Miracle starting from bicycles' by Seung-Hyun Oh, 'Letter written in mind' by Jong-Sun Hwang.

On May 28, 2011, the Hemophilia Study Group was officially launched at the spring academic seminar of The Korean Society of Hematology. As a Hemophilia Study Group which is a gathering of hemophilia care physicians and researchers was set up, the improvement and research of a national hemophilia treatment environment is expected to proceed more vigorously.

KHF entered into a mutual agreement with the Chung-Ang University Hospital on medical treatment and surgical operation for hemophilia patients on June 14 2011. This action was to confirm the partnership continued after treating hepatitis C patients in 2007.

With this, one more general hospital was added to the list of general hospitals, which specialize in treating hemophilia patients, followed by 3 KHF clinics, 10 hemophilia treatment centers by the Ministry of Health and Welfare, Kyung Hee University Hospital at Gangdong, which operates hemophilia Surgery Center, Inha University Hospital which made an agreement with KHF on January 4, 2008.

After test-operating 'Call Center' for two months from May to June to meet the emergencies and respond to inquiries related to bleeding that occurs after on-duty hours of KHF's executive office and affiliated clinics, KHF operated it formally from July 1.

The Call Center is operated as a call forwarding system of various phones of KHF from 6:00 p.m. to 10:00 p.m., after working hours on weekdays and Saturdays, and 8:00 a.m. to 10:00 p.m. on holidays.

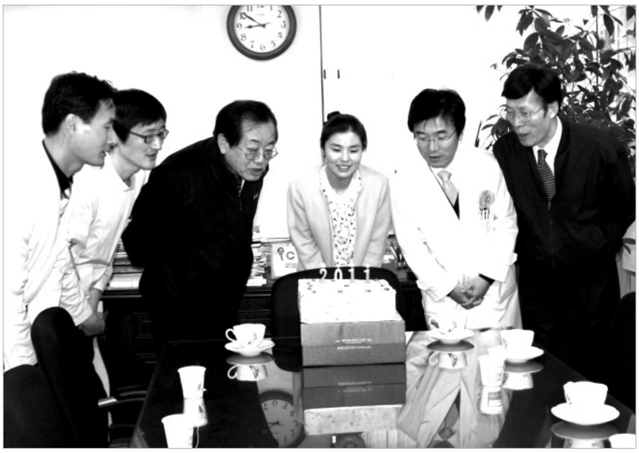
Its main consultation services are as follow: △ Information of factor concentrates, medicine holding hospital and medical staff △ Basic first aid and basic medicine capacity guide △ Medicine capacity guide according to bleeding parts and seriousness △ Requesting medical staffs aid for patients coming to other hospitals emergency rooms and so on.

In Korea, a 20-year-old man is referred to as 'Yak Kwan'. It means that he has reached 20 years of age in adulthood to celebrate his coming of age, but there is some room for more mental growth and development. These words are also used frequently to express in a good sense that a young person tends to challenge toward the world without fear and even if he falls down and collapses, immediately he can stand up straight to achieve his goal again.

While KHF marks the 20th anniversary, we won't be satisfied with its achievements so far. To the contrary, it will make every effort to improve the quality of life for hemophilia patients without fear of failure.


대한혈액학회 혈우병 연구회 창립총회
일시: 2011년 5월 28일 (토) 12:30~13:30 장소: 그랜드힐튼호텔 Flamingo Room


20th Anniversary
사회복지법인 한국혈우재단
설립 20주년
20th Anniversary
Korea Hemophilia Foundation
LOTTE


2011


2011년 한국혈우재단 Workshop



Activities in 2011

The Korea Hemophilia Foundation (KHF) set up the project goal for the year 2011 'to abolish various restrictions upon the treatment of hemophilia patients and to improve the quality of life for hemophilia patients with substantial treatment'. In addition to this, it will concentrate its efforts on △ activities to abolish restrictions upon hemophilia treatment △ arrangement of a practical care plan for people in the hinterland and the underprivileged △ providing ongoing patient education and information △ support for research and academy related to hemophilia

KHF allocated about $2,695,000 to those projects in 2011. Major activities are as follows:

1. Medical Expenses Support

Medical expenses support programs starting from 2001, for rare and incurable disease patients, has provided huge help to improve the quality of life for hemophilia patients in Korea. A total of 90% of hemophilia medical expenses are covered by public medical insurance, and the remaining 10%, which has been a patient economic burden, is now gone, owing to the support for rare and incurable diseases patients.

However, because there are people who exceed the criteria of income and property and have to pay non-formulary medical expenses not covered by public medical insurance, KHF has been trying to reduce the economic burden of hemophilia patients as much as possible.

△ Support for Dropouts Not Aided from Government:

By the end of 2011, the dropout patients who exceed the income and property criteria decided on a medical expenses support program for rare and incurable disease patients, mounting up to 255, which was 12% of the total 2,103 registered patients. In that case, although the patient medical payment limit was

applied, they have to pay medical bills from $1,740 up to $3,480 a year. It often occurs that because of their personal choices that they are dropouts from the government medical expenses support, they refuse proper treatments even with bleeding. KHF supplies 50% of medical bills paid by a patient (limit of $1,740 a year) to provide minimal medical treatment. In the last 2011, about $205,000 was paid to a total of 192 patients.

△ Non－Formulary Medical Expenses Support:

One of the frequent problems in public medical insurance is that non-formulary medical expenses are not covered. In particular, in case of low-income patients such as economically disadvantaged care recipients, it is very difficult for them to pay non-formulary medical bills that occur when they undergo intensive treatment such as surgery. KHF pays the non-formulary medical expenses except the upper-grade sickroom fee for the hospitalized patients and expensive non-formulary test fees such as MRI, which are essential to treat hemophilia for the ambulatory patients (limit of $2,610 a year). In 2011, it provided all of 41 patients with about $37,400.

△ Medical Expense Support for Chronic Hepatitis Patients

KHF has supported HCV treatment expenses since 2007. Patients who undergo double pains of hemophilia and hepatitis C received treatment in KHF clinics and various hemophilia treatment centers. In 2011, free ultrasound test was expanded from 1 time to 2 times. And all 49 patients were provided with $6400 for chronic hepatitis treatment and ultrasound test.

△Non－Formulary Test Fee Support:

KHF supports test fees for von Willebrand disease and DNA analysis not covered by public medical insurance, and in 2011, $18,260 was provided for a total of 277 patients, 86 patients for DNA analysis and 191 patients for other coagulation factor deficiencies tests, including von Willebrand disease.

△ Emergency Special Aid:

Since 2007, KHF has carried out the ermergency special aid program to provide up to $1,740 per person as non-medical expenses in an emergency for lower-income patients who are hesitant about being treated at a hospital even in an emergency. In 2011, one patient was supplied with $330.

△ Other Medicine Support:

Patients can be provided with a portion of medicine expenses when being inoculated against hepatitis B at 3 KHF clinics. In 2011, 110 persons were supplied with $2,430.

△ Affiliated Clinic Operating Costs Support:

Three affiliated clinics run by KHF are in charge of approximately 70% of domestic hemophilia patients treatment. In the Korean medical environment, however, it is very difficult to operate the affiliated clinics normally while focusing only on treating hemophilia patients. To overcome these difficulties, $617,000 was provided for maintenance and operating of the clinics.

2. Patient Education and Support Program

It is most important to prevent bleeding for hemophilia patients. However, to prevent all bleeding completely is not easy. So when bleeding occurs, immediately the patient, for himself, or his family should administer a blood coagulant. In addition, even after the bleeding stops, he needs rehabilitation and exercise to restore physical function before the bleeding.

If the patient is able to do all this process for himself, he can maintain his healthy life. The self-management is absolutely required and very important for hemophilia patients. KHF's education and support program to improve the self-management ability of hemophilia patients and their families was also one of its most important projects.

△Hemophilia Seminar

The 5th hemophilia seminar to provide information about hemophilia care to hemophilia patients and their families was held at Hwasun Hospital of Chonnam National University. A total of 169 people participated in the seminar and $12,600 was used.

△ Education Booklet Publication

The newsletter, 'Kohem', to provide an information related to hemophilia for hemophilia patients and their families is issued bimonthly, and the essay book, 'amusing dreams for tomorrow…', which consisted of the various stories submitted to the story competition conducted to mark the 20th anniversary of KHF was published. 'Hemophilia and a healthy baby', which is an education booklet for the family of a patient newly diagnosed as hemophilia, was additionally printed and, the hemophilia annual report that introduces one-year projects of KHF and provide statistical data related to hemophilia patients was published. The total budget was $3,870.

△ Orthopedic Care Support:

The medical staff of the Hemophilia Surgery Center of Kyung Hee University Hospital at Gangdong conducted orthopedic care for hemophilia patients six times on Saturday at the KHF seoul clinic, and 92 people received the treatment. The budget was $10,400.

△ Patients Shelter Opening & Operational Support

The lease contract of a shelter in Daegu expired, and the shelter was moved into a new place to help local hemophilia patients to use the hospital and use the shelter for branch gathering and educational purposes. In 2012, a shelter near Presbyterian Medical Center in Jeonju is scheduled to open for the patients in Jeollabuk province and be operated to help rehabilitation after surgery or severe bleeding. In 2011, the budget was $66,000.

△ Patients Event Support:

KHF supported the cost of Children's Day events and summer camp hosted by "Cheongshim", a gathering of hemophilia patients in Jeollanam and Jeollabuk province and dispatched 15 medical staff including doctors and nurses. KFH also supported 13 medical personnel and necessary medicines to Kohem summer camp. The budget was about $45,000.

△ Employment & Education Support

Hemophilia patients often stop their school work due to frequent bleeding, and because of the lack of social awareness about hemophilia, they suffer a

disadvantage in the employment process. KHF offers education fee for their scholarship certification and employment-related education to hemophilia patients so that they do not suffer a disadvantage in social activities such as education or employment. Recognized academic education and employment-related education is supported. In 2011, approximately $5,500 was provided to support seven people.

△Swimming Payment Support:

Swimming is highly recommended to hemophilia patients by all doctors. KHF provides swimming instruction fee for 5 months a year for hemophilia patients to be actively involved in swimming. (50% of fee for the insured, 90% of fee for health care recipients) In 2011, $5,560 was provided for 67 patients. (from 2012, a support period was extended to six months.)

△Patients Welfare Promoting Project Trust:

Patients welfare promoting project was trusted to hemophilia patients group, Cheongshim gathering, to advance the welfare of patients and to help them use affiliated clinics. The related support expense was $23,5000.

△Specified Donation Support:

The staff of Green Cross Corp., which is KHF's biggest sponsor, delivered a one-year sponsorship to six low-income patients, and the specified donation of the Social Workers Association was delivered to two patients. The total amount of the specified donation was approximately $19,200.

△Other Public Activities & Events:

KHF sent year-end gifts to 274 children patients. A total of $55,700 was alloted for counseling of newly diagnosed patients, injection training, guidance letters sending service and homepage operation.





3. Homecare Service

Through the homecare service of KHF, one social worker and 5 counselors, consisting of hemophilia patients and their families, take active roles in local areas such as Seoul and 4 nationwide provinces of Gyeongsangbuk, Gyeongsangnam, Jeollabuk and Jeollanam and take charge of home visiting counseling and education for patients, consulting about central and local government's supports and resolving public complaints.

In 2011, 1,444 consultation meetings were performed for 757 people, equivalent to 34.2% of all registered patients. Visiting counseling in public facilities such as down-block offices and public health center in charge of patients' residence, social community in hospital and school health care center were conducted 48 times.

The number of patients using the night call center was 50. And also 43 times various events like military camp, newly registered patients' family meeting, multi-cultural family swimming classes were held, and a total of 882 people attended. Employment aid programs such as employment-related information offers and company cooperation support were conducted, so that 21 people were consulted and introduced to public facilities and companies. All of the cost for homecare services was $120,000.

4. Support for Research and Academy

We have to present the objective and scientific data related to hemophilia patient treatment to the relevant government agencies and persuade them for 'Activities for the abolition of hemophilia treatment restriction' to be set up our main task of the year 2011. In addition, to help national hemophilia care physicians and researchers to study hemophilia is also one of the important roles of KHF.

△ Hemophilia Research Support

KHF has funded hemophilia-related research expenses every year since 2001. In 2011,

“Predictability of FⅧ: C Level by Clot Waveform Analysis” by Soon-Ki Kim, Professor of Inha University and “Mutation analyses in Korean patients with hemophilia” by Hee-Jin Kim, Professor of Sungkuynkwan University were funded about $27,000. Since 2001, a total of 26 researches were supported by KHF.

△ Hosting Academic Conference & Participation Support

The 2011 Korea Hemophilia Symposium was held by KHF to provide the latest hemophilia treatment information for national hemophilia care doctors. In addition, KHF applied to participate in international academic conferences such as WFH Musculoskeletal Congress, 2011 East Asia Hemophilia Forum, 2011 ISTH(2011 International Society of Thrombus Hemostasis). The total amount of financial support was $73,900.

△ Other Activities:

KHF has supported the subscription of the official academic magazine of WHF, ‘Haemophilia Journal’, to provide the latest hemophilia treatment information for national hemophilia care doctors and persons in charge of related facilities. Furthermore, it has run the Medicopharmacy Council to develop the policy in the field of medical science and pharmacy. The budget was $13,900.


MiSO
Open Run 4pm, 8pm


신나는
수영

In 1990, when KHF was first established, there were only three designated hospitals for hemophilia in Korea. These included the Shinchon Severance Hospital of Yonsei University, Chonnam National University Hospital and Busan Paik Hospital of Inje University. At that time, hemophilia patients had considerable trouble getting the treatment that they needed.
KHF and KHF Seoul Clinic were established at the same time so that hemophilia patients could have access to specialized treatment more easily (February 11, 1991). After that time, Gwangju clinic was opened in 2006, and Busan clinic was opened in 2007.

KHF Clinics - 2011

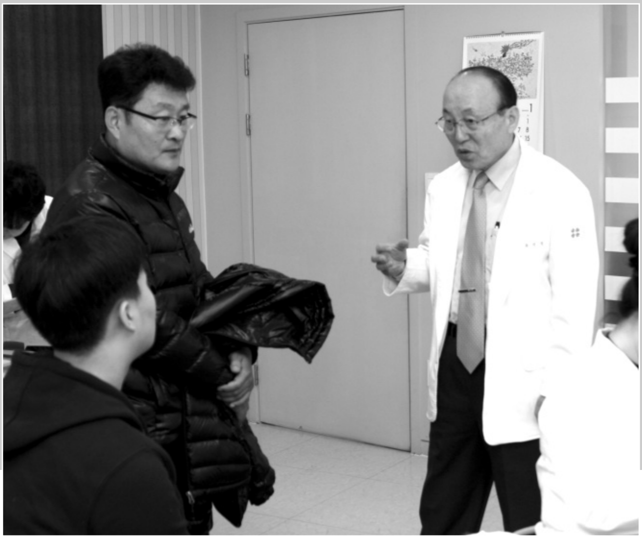
1. KHF Seoul Clinic

During the year 2011, 1,270 patients, out of the total of 16,798, received treatments at Seoul clinic. This number is equivalent to 60% of the total registered patients. The days of total treatment were 301 days, and 56 patients were treated a day. Every Tuesday, night care service was opened till 8:30 pm. It was conducted 44 times and 213 people (120 actual patients) received the treatment.

A total of 3,978 people (349 actual patients) received physical therapy, and the aquatic exercise therapy, which was operated from December 2008, gave care to 538 people (41 actual patients) for 154 days a year. 26,658 clinical pathology tests (for 1,218 people) were conducted, and 195 DNA analyses were performed.

In addition, 527 patients in total received 1,846 X-ray examinations, and 270 patients took 280 electrocardiogram tests, splints, hearing tests and ultrasonography.

Hepatitis C therapy that KHF clinics have conducted since 2007 gave medical treatment to 124 patients



and 98 patients among them (79%) were completely cured. In 2011, 237 patients (80 actual patients) received hepatitis C treatment.

Home-visiting medical care for patients with limited mobility residing in the local province was performed 45 times for 35 patients, and for 162 patients in total. With the help of the medical staff of Kyung Hee University Hospital at Gangdong, orthopedic medical care was carried out 6 times, and 92 patients received the treatment. Also, a rehabilitation clinic for patients with chronic hemophilic arthropathy was started as a pilot project. This project has been performed once a week in cooperation with the Department of Rehabilitation Medicine, Chung-Ang University Hospital. On November 16, 2011, the initial treatment began and until December, 20 patients received treatment twice.

As for hemophilia patient education, 24 patients received a self-injection training held by KHF nine times. The local visiting education were held all 3 times in Daegu, Gangwon, and Gyeonggi including Kohen summer camp, and 236 patients took part in the program.

2. KHF Gwangju Clinic

In 2011, the KHF Gwangju clinic gave medical treatment to 3,809 in total (171 actual patients).

Average daily treatment capacity was 14.4 patients. A total of 1,153 patients got physical therapy and 2,975, laboratory tests were performed. Through injection training of Gwangju clinic, nine patients were able to inject themselves.

3. KHF Busan Clinic

In 2011, the KHF Busan clinic provided tretment 3,180 times. Actual patients were 198 and averaged 12 a day.

A total of 1,193 patients received physical therapy, and 3,521 laboratory tests were performed. Through 4 times of injection training, 8 patients received self-injection training. A total of 5 patients participated in 1 physical therapy education.

Do I Deserve Respect Instead of Pity?

Kim, Young Jung

The Fate Which was Uncovered at the Age of 32

It all started with a small cut, about the size of a newborn baby's nail.

On one spring day, at the age of 32, I made the silly mistake of biting my tongue while I was having lunch. I pressed down on it with a tissue and just a little blood came out. However, it was just the beginning. My fate from birth would soon change my life. I continued to bleed into the night. I could not go to sleep because of the blood that was going down my throat, so I went to the local clinic and had the cut on my tongue stitched. It was just a minor procedure and the bleeding soon stopped. But the next day, I discovered that the wound had swelled and it formed a hematoma. The hematoma was so big that when I closed my mouth it could touch the roof of mouth. A few days later, the swelling worsened until the hematoma burst and then the bleeding was unable to be stopped.

An intern at the university medical center that I went to asked me a question that left me speechless, "How on earth did you manage to bite your tongue like this?" There was no treatment other than to press down on the wound with a bandage. Finally, the bleeding stopped after compressing the wound for an hour and the intern released me from the hospital. However, in less than 10 minutes, the bleeding started again and I had to rush back to the hospital. I could still see the blood stains on the street from the blood that I had spit up a few hours ago. Feeling angered and frustrated, I wanted to say something to the intern who had cared for me previously, but by the time I had returned to emergency room, he had already left and another doctor was in charge of ER. Over the course of the next week, I was transferred from the ER to the ENT clinic and then to the department of hematology. I ended up with a piece of paper that provided a medical diagnosis of my condition: Hemophilia, type A, with a deficiency of coagulation factor 8 and a value of 2.8.

A ENT surgeon who had performed the surgery to remove the hematoma from my tongue said, "Honestly, this is the first time for me to come across a hemophilia patient." This was not surprising as the number of hemophilia patients are much less than the number of doctors. "In most cases, when bleeding occurs during tongue operation, we heat tissue with electricity to stop bleeding, but in your case, this procedure can cause more bleeding which can result in death. We can start surgery only after injecting coagulation factors for a few days and following the instructions of a hematologist." And he added, “ … and how come you did not know about your medical condition up until now?”

My Life and My Disease

People around me often ask how I could have been unaware of my disease until that age. The truth is that I did know about it, but there was no doctor’s diagnosis. After washing my face, everytime I would blow my nose, there would be blood stains on the tissues. It was a lot worse when I was a child. Whenever I wash my face, my nose would start to bleed. People used to ask me why I had so many scars on my knees. They were not scars from surgery, but stretch marks that came from the rapid stretching skin. The stretch marks came from internal bleeding in the joints which resulted in massive swelling. When my baby teeth started to fall out, I used to have bleeding that lasted for several days. When I got up in the morning, I had blood all around my mouth.

I used to limp when I was an elementary school student. The pain in my knees and ankles used to come and go. However, even there was not much pain, I could not walk naturally like everyone else. Some kids used to make fun of how I walked. Even worse, some of them would mimic the way I walked. One day, when I was in middle school, I found something as I was looking at my shoes which I had taken off. I noticed that my shoes were twisted abnormally and from this I realized that something is wrong with the direction of my ankles. I practiced walking along the street in a straight line. Eventually, the practice paid off. The muscle of the legs had developed properly and I was able to walk straight again.

By the time I was a teenager, I had been to orthopedic clinics so many times to manage the pain in my leg. Even though sometimes I could not bend my knees because of pain, the exact cause of the pain was unclear. The only medical diagnosis that I received was ‘pediatric arthritis’, but this simply described my medical condition. There are many causes of arthritis, but no one was able to tell me where the pain came from and what caused the arthritis.

When I was in the 1st grade of middle school, I had a small cut stitched up. But the bleeding lasted for several days. The doctor who put the stitches in said that he had never seen anything like it and asked me to go to a bigger hospital. I went to a medical center in Pusan, which is the second largest city in Korea with a population of 4 million, and stayed there around 2 weeks. But still I was not diagnosed as having hemophilia. The doctor told me that I might have a low blood platelet count. Medically, thrombocytopenia, which means a decrease of platelets, and hemophilia are totally different diseases. They simply must have not performed the necessary examination to see if a patient had hemophilia or not. Maybe at that time (the 1980s), they might not have a hemophilia examination.

My uncle, who had similar symptoms as me, also went through many medical examination, and he did not receive a clear diagnosis from anyone. After I was diagnosed as having hemophilia in 2006, he was able to be diagnosed about his own disease at the age of sixties. When my uncle asked doctors, “I think I have bleeding problem. Is that a disease? How can it be cured?” doctors answered they were not sure. That happened a lot of times. And now, when he consulted doctors about his nephew’s hemophilia, with a diagnosis paper in his hand, then doctors said "Yes, you have hemophilia."

I assume that even now, in some areas, it would be hard to run tests for hemophilia and I am sure that many patients are suffering from it without even knowing what it is that's causing them all the bleeding and the pain. Rare diseases which do not afflict many patients are difficult to be diagnosed. Many doctors never have a chance to encounter a hemophilia patient over their entire professional career. Unless a doctor suspects the possibility of a patient having hemophilia, he or she would not even consider running a hemophilia test on a patient. For the longest time, I trusted my doctor's word, so I did not even think of going to a different hospital to get a second opinion. I was not able to find out about my disease until I was 32 years old and it might not have been possible to get an accurate diagnosis if I had met a different doctor at the time that I did. This is why I did not know about my disease up until then.

Anger, Despair and Resentment

While I was waiting in my hospital bed for the surgery to remove the hematoma, I could not help thinking to myself, "Why me? What have I done so wrong that I have to suffer this much? An incurable disease …. Why me?" Anger, despair, and resentment towards everything around me made me painful. Tears were rolling down.

I thought I was so silly. A patient with a hereditary disease who majored in genetic…. I graduated from Seoul National University with a degree in molecular biology. Why did I not know about my own hereditary disease after all this time of studying genetics and biochemistry? Why didn't I even suspect my disease? I started to disparage myself. "How did I get here? How should I live from now on?"

Even after I left the hospital, came back home and went back to work, I could not get myself calmed down. I felt even more pain in my legs when I walked, so I bought a cane to get around. I could sense that people were looking at me. When I was little, I had a limp. I thought I would never have to go through that again because I got stronger in my twenties. But I was starting to collapse again in my thirties.

People usually react in three different ways when they find out that I am suffering from hemophilia. First, because I look physically fine on the outside, some people think that I am exaggerating. But I am really in pain. Second, some people feel sorry for me and show sympathy, but I don't want people to feel pity for me. Third, some people look at me as if I am from another planet, but I am not a monkey in the zoo.

Most people find it interesting and ask me various questions. I can deal with most of the questions that people ask, but honestly, I'd rather not talk about it. The most absurd question that made me really upset was something like, "Do you continue to bleed when you get a mosquito bite?" I just do not know how to react to a question like this.

It felt like I had rage waves in my heart that could sweep myself. No religion or philosophy could comfort me. Time just passed by. I looked the same on the outside, I was getting emotionally drained.

A Way to Heal My Soul

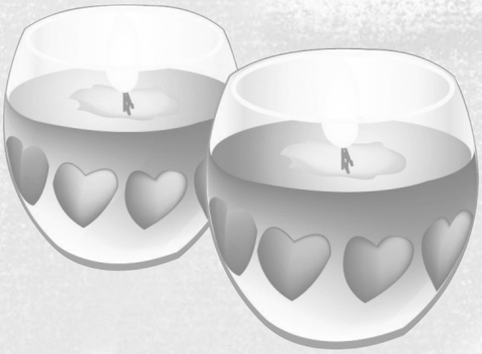
It was just another gloomy day when I happened to see an interview of Janet Lee, who is an famous Korean-American professional billiard player, on TV. When she lifted her hair, which tied up in a pony tail, I could see a big scar on her back. She had metal pins inserted into her back because she was suffering from scoliosis, which is an abnormal curvature of the spine. I had heard the name before, but it was the first time to actually find out about her disease. She can not bend her spine like a bow when she plays pool, so she plays with a straight back and only bends at her pelvis. She has been playing like this for years. Despite her physical disadvantage, she has won many championships. In the interview she said, “My disease... it was a big tragedy for me. If I just let myself go, people would just pity to me. But I wanted to get respect instead of pity.”

Tragedy, pity, and respect…. It was a clue to awakening. Janet Lee, who was only a couple years older than me was asking me if I would live a life with people feeling pity for me or having respect for me. Pity and respect, these two words have been a source of motivation for my life ever since.

For over 30 years, I had never stopped living my life. Even when I had to take pain killers while I was studying for my exams, I did my best. I always tried harder than anyone else around me and was able to graduate from Seoul National University. I was happy about what I had accomplished in my life.

It is interesting how the human mind works. When I did not know about my disease for sure, I was able to endure the pain, but as soon as I found out about my disease, my mind just could not stand it anymore. Now even with a little pain, I was terrified and depressed. The question, “Why me?” was destroying me. My family started to get concerned with how I was coping and this made me more anxious and sensitive. I tried to regain my confidence, thinking, “If she can overcome her physical disability and get people’s respect, why not me?”

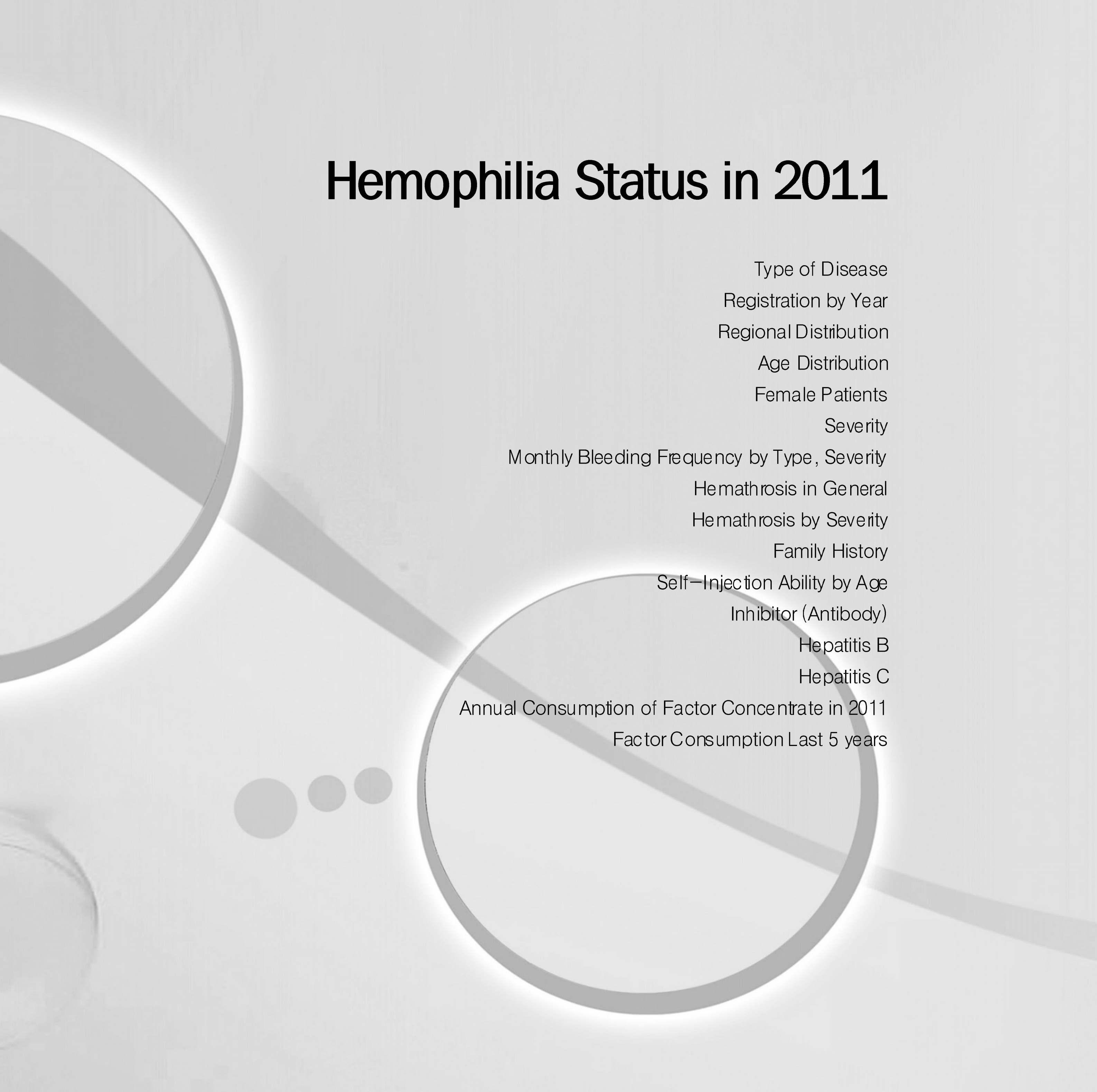
And I try. I do try to be confident. But my physical condition has not changed at all. I still have hemophilia and suffer from symptoms, and this will not be changed forever. Sometimes I think that my life as a hemophilia patient is like walking through a dense glass. Every step I take the glass will block my way and only gives a tiny space in which to move forward. My life is full of limitations. I have never forgotten even for one day that I have hemophilia. I am sure Janet Lee also feels the metal pins in her back every single day. When my legs and ankles are painful, when I see blood stains on tissues after blowing my nose, when my mouth bleeds for no reason, when I hit my limbs on something and start to swell, and when I have to reach out for my cane again … I become devastated. Let myself be devastated for a moment … just for a moment, just for a little moment.



However, I soon get myself together, stand up again, and remind myself how much I’d rather get respect from other people than pity. I do not have time to be sentimental now. I have a family whom I have to take care of and people waiting for me at work. They are all watching me. I think to myself that I have to try a lot harder than others. It is just like what I have been doing.

Sometimes, I look around people in the metropolis of Seoul where I live. I take a look at people on the subway, going back home. Most of them look exhausted and unhappy, some with their eyes closed, dozing off. I think that how many people in here do not have a story to tell about their lives and how many of them are not experiencing any problems in their lives. After all, my worst enemy may have been myself.

Today, I think to myself again, “Don’t let anyone suffer because of me. Do I deserve to have others’ respect instead of pity?”



Hemophilia Status in 2011

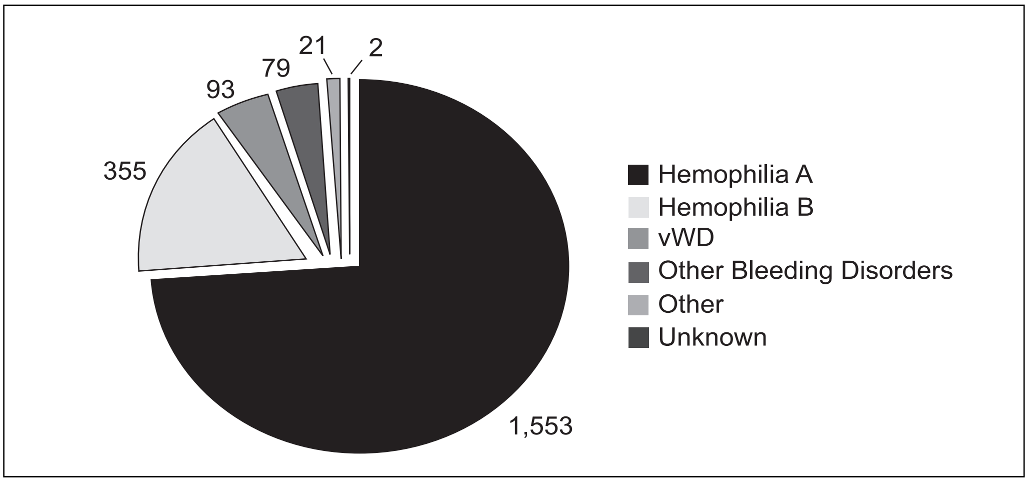
Type of Disease
Registration by Year
Regional Distribution
Age Distribution
Female Patients
Severity
Monthly Bleeding Frequency by Type, Severity
Hemathrosis in General
Hemathrosis by Severity
Family History
Self–Injection Ability by Age
Inhibitor (Antibody)
Hepatitis B
Hepatitis C
Annual Consumption of Factor Concentrate in 2011
Factor Consumption Last 5 years

Hemophilia Status in 2011

In 1991, after the establishment of KHF, the work of registration and management of hemophilia patients was transferred by the Ministry of Health & Welfare to KHF.
Nowadays, each medical facility contact KHF once a patient is diagnosed with hemophilia.
In total, 2,103 people with hemophilia and other bleeding disorders were registered by KHF as of December 31, 2011.

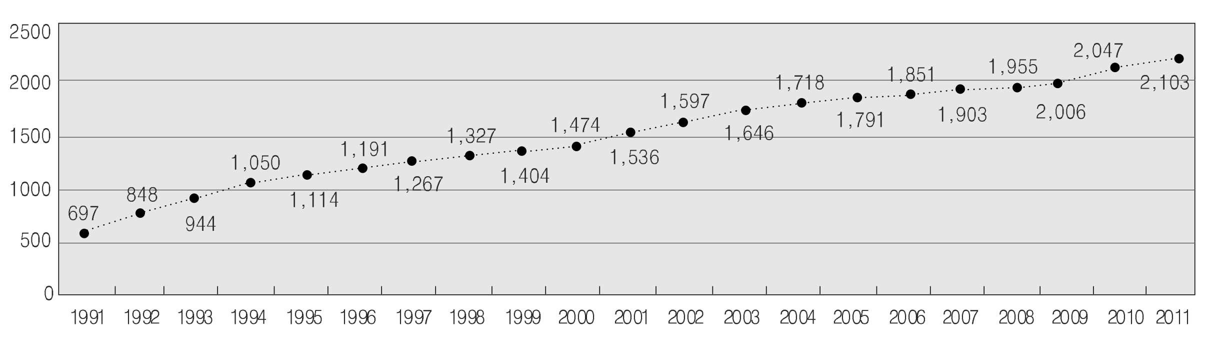
Type of Disease

Type	No. of Patients	Rate	New Patients in 2011	Rate
Hemophilia A	1,553	73.8%	37	58.7%
Hemophila B	355	16.9%	13	20.6%
vWD	93	4.4%	5	7.9%
Factor I Deficiency	6	0.3%	0	0.0%
Factor V Deficiency	4	0.2%	0	0.0%
Factor VII Deficiency	31	1.5%	4	6.3%
Factor X Deficiency	2	0.1%	1	1.6%
Factor XI Deficiency	14	0.7%	1	1.6%
Factor XII Deficiency	3	0.1%	0	0.0%
Factor XIII Deficiency	5	0.2%	0	0.0%
Multi Factor Deficiency	8	0.4%	0	0.0%
Acquired Coagulation Factor Deficiency	6	0.3%	1	1.6%
Other	21	1.0%	0	0.0%
Unknown	2	0.1%	1	1.6%
Total	2,103	100.0%	63	100.0%



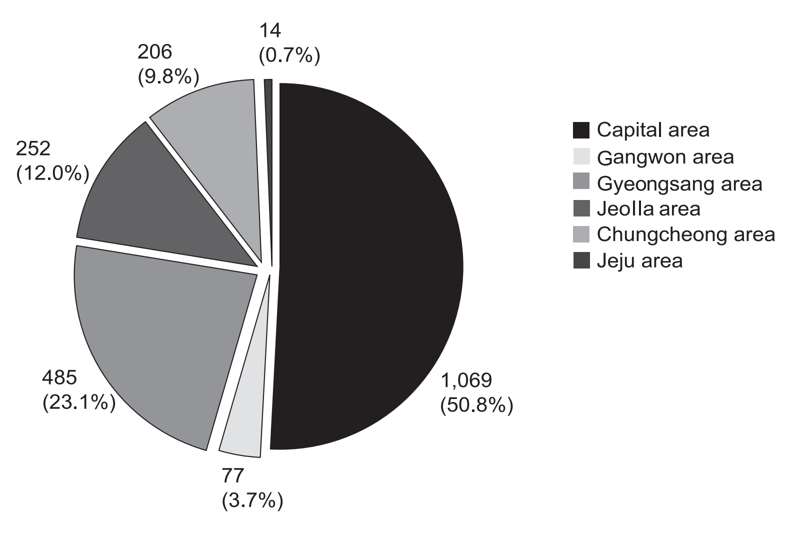
Registration by Year

Year	Hemophilia A	Hemophilia B	vWD	Other	New Patients	Death	Total
1991	590	105	2	1	696	2	697
1992	139	17	0	1	157	6	848
1993	84	12	1	4	101	5	944
1994	94	14	4	0	112	6	1,050
1995	54	9	5	2	70	6	1,114
1996	66	9	4	2	81	4	1,191
1997	63	13	5	2	83	7	1,267
1998	45	12	10	2	69	9	1,327
1999	65	12	1	3	81	4	1,404
2000	55	14	5	4	78	8	1,474
2001	41	11	10	8	70	8	1,536
2002	43	10	10	5	68	7	1,597
2003	32	18	4	5	59	10	1,646
2004	44	19	7	8	78	6	1,718
2005	42	21	4	12	79	6	1,791
2006	43	12	3	6	64	4	1,851
2007	38	13	2	6	59	7	1,903
2008	36	16	2	9	63	11	1,955
2009	39	12	5	5	61	10	2,006
2010	20	8	4	13	45	4	2,047
2011	37	13	5	8	63	7	2,103
Total	1,670	370	93	107	2,240	137	



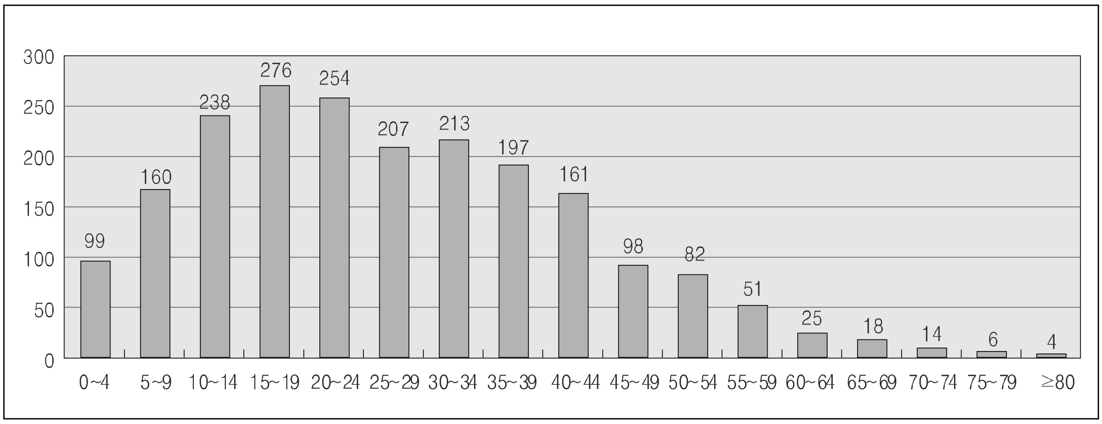
Regional Distribution

Region	Hemophilia A	Hemophilia B	vWD	Other	Total	Rate
Seoul	364	66	26	27	483	23.0%
Busan	89	21	2	4	116	5.5%
Daegu	88	16	5	2	111	5.3%
Incheon	63	15	6	8	92	4.4%
Gwangju	53	28	4	3	88	4.2%
Daejeon	59	7	0	2	68	3.2%
Ulsan	32	1	1	2	36	1.7%
Gangwon	65	9	2	1	77	3.7%
Gyeonggi	356	91	21	26	494	23.5%
Gyeongsangnam	95	15	2	7	119	5.7%
Gyeongsangbuk	62	19	16	6	103	4.9%
Jeollanam	52	27	2	5	86	4.1%
Jeollabuk	63	10	1	4	78	3.7%
Chungcheongnam	53	14	5	3	75	3.6%
Chungcheongbuk	50	11	0	2	63	3.0%
Jeju	9	5	0	0	14	0.7%
Total	1,553	355	93	102	2,103	100.0%



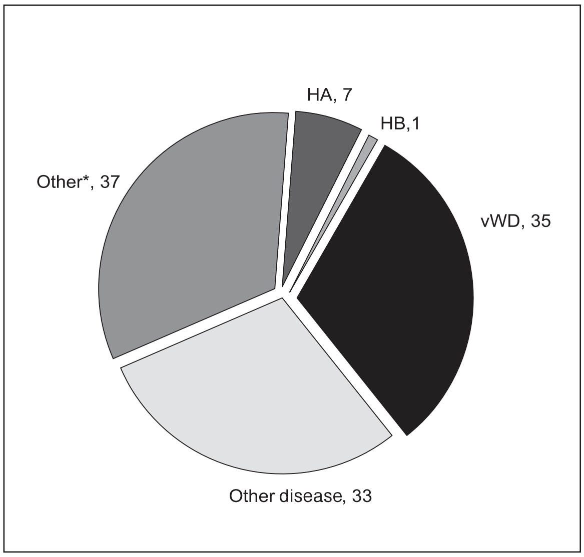
Age Distribution

Age	Hemophilia A	Hemophilia B	vWD	Other	Total	Rate
0~4	74	20	0	5	99	4.7%
5~9	106	36	3	15	160	7.6%
10~14	165	46	13	14	238	11.3%
15~19	192	38	18	28	276	13.1%
20~24	189	38	17	10	254	12.1%
25~29	155	35	11	6	207	9.8%
30~34	169	33	6	5	213	10.1%
35~39	151	30	9	7	197	9.4%
40~44	123	31	5	2	161	7.7%
45~49	83	11	2	2	98	4.7%
50~54	64	15	2	1	82	3.9%
55~59	40	10	1	0	51	2.4%
60~64	18	4	1	2	25	1.2%
65~69	10	2	3	3	18	0.9%
70~74	8	4	1	1	14	0.7%
75~79	3	2	1	0	6	0.3%
≥80	3	0	0	1	4	0.2%
Total	1,553	355	93	102	2,103	100.0%



Female Patients

Type of Disease	No. of patients	Rate
Hemophilia A	7	6.2%
Hemophilia B	1	0.9%
vWD	35	31.0%
Factor I Deficiency	3	2.7%
Factor V Deficiency	2	1.8%
Factor VII Deficiency	15	13.3%
Factor X Deficiency	0	0.0%
Factor XI Deficiency	4	3.5%
Factor XII Deficiency	1	0.9%
Factor XIII Deficiency	4	3.5%
Multi Factor Deficiency	1	0.9%
Acquired Factor Deficiency	3	2.7%
Other*	37	32.7%
Total	113	100.0%



※Other : Include carriers who have bleeding symptoms.

Female Patients by Age Distribution

Age	Hemophilia A	Hemophilia B	vWD	Other Disease	Other*	Total
0~4	1	0	0	0	0	1
5~9	2	0	2	5	3	12
10~14	0	0	3	2	4	9
15~19	2	0	6	10	4	22
20~24	0	0	5	3	2	10
25~29	0	0	3	3	2	8
30~34	2	0	3	3	2	10
35~39	0	1	4	2	7	14
40~44	0	0	3	1	3	7
45~49	0	0	2	1	4	7
50~54	0	0	2	0	1	3
55~59	0	0	0	0	3	3
60~64	0	0	0	0	2	2
65~69	0	0	1	2	0	3
70~74	0	0	0	1	0	1
75~79	0	0	1	0	0	1
≥80	0	0	0	0	0	0
Total	7	1	35	33	37	113

Severity

Type	Severe	Moderate	Mild	Unknown	Total
Hemophilia A	1,049 (67.5%)	324 (20.9%)	172 (11.1%)	8 (0.5%)	1,553 (100.0%)
Hemophilia B	210 (59.2%)	99 (27.9%)	42 (11.8%)	4 (1.1%)	355 (100.0%)
Total	1,259 (66.0%)	423 (22.2%)	214 (11.2%)	12 (0.6%)	1,908 (100%)

※ Severe : <1%, Moderate : 1.0~5%, Mild : >5.1%

Monthly Bleeding Frequency by Type, Severity

Type	Severity	<1	1~2	3~4	5~8	≥9	Unknown
Hemophilia A	Severe	42 (4.0%)	225 (21.4%)	424 (40.4%)	205 (19.5%)	23 (2.2%)	130 (12.4%)
	Moderate	98 (30.2%)	89 (27.5%)	72 (22.2%)	10 (3.1%)	1 (0.3%)	54 (16.7%)
	Mild	79 (45.9%)	16 (9.3%)	3 (1.7%)	0 (0.0%)	0 (0.0%)	74 (43.0%)
	Unknown	1 (12.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	7 (87.5%)
	Total	221 (14.2%)	331 (21.2%)	500 (32.1%)	215 (13.8%)	24 (1.5%)	266 (17.1%)
Hemophilia B	Severe	23 (11.0%)	53 (25.2%)	84 (40.0%)	11 (5.2%)	0 (0.0%)	39 (18.6%)
	Moderate	40 (40.4%)	13 (13.1%)	7 (7.1%)	1 (1.0%)	1 (1.0%)	37 (37.4%)
	Mild	20 (47.6%)	2 (4.8%)	2 (4.8%)	0 (0.0%)	0 (0.0%)	18 (42.9%)
	Unknown	0 (0.0%)	1 (25.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (75.0%)
	Total	84 (23.5%)	69 (19.4%)	94 (26.1%)	12 (3.4%)	1 (0.3%)	98 (27.4%)

Hemathrosis in General

Type	Hemathrosis	None	Total
Hemophilia A	986(63.5%)	567(36.5%)	1,553(100.0%)
Hemophilia B	154(43.4%)	201(56.6%)	355(100.0%)
vWD	7(7.5%)	86(92.5%)	93(100.0%)
Other	11(10.8%)	91(89.2%)	102(100.0%)
Total	1,158(55.1%)	945(44.9%)	2,103(100.0%)

Hemarthrosis by Severity

Type	Severity	Hemarthrosis	Unkown	Total
Hemophilia A	Severe	793(75.6%)	256(24.4%)	1,049(100.0%)
	Moderate	164(50.6%)	160(49.4%)	324(100.0%)
	Mild	29(16.9%)	143(83.1%)	172(100.0%)
	Unknown	0(0.0%)	8(100.0%)	8(100.0%)
	Subtotal	986(63.5%)	567(36.5%)	1,553(100.0%)
Hemophilia B	Severe	133(63.3%)	77(36.7%)	210(100.0%)
	Moderate	20(20.2%)	79(79.8%)	99(100.0%)
	Mild	1(2.4%)	41(97.6%)	42(100.0%)
	Unknown	0(0.0%)	4(100.0%)	4(100.0%)
	Subtotal	154(43.4%)	201(56.6%)	355(100.0%)
Total		1,140(59.7%)	768(40.3%)	1,908(100.0%)

Family History

Type	Identified	None	Total
Hemophilia A	744(47.9%)	809(52.1%)	1,553(100.0%)
Hemophilia B	147(41.4%)	208(58.6%)	355(100.0%)
vWD	33(35.5%)	60(64.5%)	93(100.0%)
Other	17(16.7%)	85(83.3%)	102(100.0%)
Total	941(44.7%)	1,162(55.3%)	2,103(100.0%)

Self-Injection Ability by Age

Age	Able	Not Able	Total No. of Patients
0~4	14(14.1%)	85(85.9%)	99(100.0%)
5~9	35(21.9%)	125(78.1%)	160(100.0%)
10~14	56(23.5%)	182(76.5%)	238(100.0%)
15~19	64(23.2%)	212(76.8%)	276(100.0%)
20~24	60(23.6%)	194(76.4%)	254(100.0%)
25~29	45(21.7%)	162(78.3%)	207(100.0%)
30~34	31(14.6%)	182(85.4%)	213(100.0%)
35~39	16(8.1%)	181(91.9%)	197(100.0%)
40~44	8(5.0%)	153(95.0%)	161(100.0%)
45~49	9(9.2%)	89(90.8%)	98(100.0%)
50~54	4(4.9%)	78(95.1%)	82(100.0%)
55~59	4(7.8%)	47(92.2%)	51(100.0%)
60~64	1(4.0%)	24(96.0%)	25(100.0%)
65~69	2(11.1%)	16(88.9%)	18(100.0%)
70~74	0(0.0%)	14(100.0%)	14(100.0%)
75~79	1(16.7%)	5(83.3%)	6(100.0%)
≥80	0(0.0%)	4(100.0%)	4(100.0%)
Total	350(16.6%)	1,753(83.4%)	2,103(100.0%)

Inhibitor (Antibody)

Type	High responder	Low responder	Transient	None	Unknown	Total
Hemophilia A	28 (1.8%)	26 (1.7%)	59 (3.8%)	1,379 (88.8%)	61 (3.9%)	1,553 (100%)
Hemophilia B	5 (1.4%)	3 (0.8%)	0 (0.0%)	324 (91.3%)	23 (6.5%)	355 (100%)
Total	33 (1.7%)	29 (1.5%)	59 (3.1%)	1,703 (89.3%)	84 (4.4%)	1,908 (100%)

※ High responder : ≥ 5BU/㎖, Low responder : 1~5〈 BU/㎖

Inhibitor by Severity (Hemophilia A)

Type	Severe	Moderate	Mild	Unknown	Total
High responder	28 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	28
Low responder	24 (92.3%)	2 (7.7%)	0 (0.0%)	0 (0.0%)	26
Transient	45 (76.3%)	12 (20.3%)	2 (3.4%)	0 (0.0%)	59
None	929 (67.4%)	295 (21.4%)	154 (11.2%)	1 (0.1%)	1,379
Unknown	23 (37.7%)	15 (24.6%)	16 (26.2%)	7 (11.5%)	61
Total	1,049 (67.5%)	324 (20.9%)	172 (11.1%)	8 (0.5%)	1,553

Inhibitor by Severity (Hemophilia B)

Type	Severe	Moderate	Mild	Unknown	Total
High responder	5 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	5
Low responder	3 (100.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	3
Transient	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0
None	199 (61.4%)	87 (26.9%)	38 (11.7%)	0 (0.0%)	324
Unknown	3 (13.0%)	12 (52.2%)	4 (17.4%)	4 (17.4%)	23
Total	210 (59.2%)	99 (27.9%)	42 (11.8%)	4 (1.1%)	355

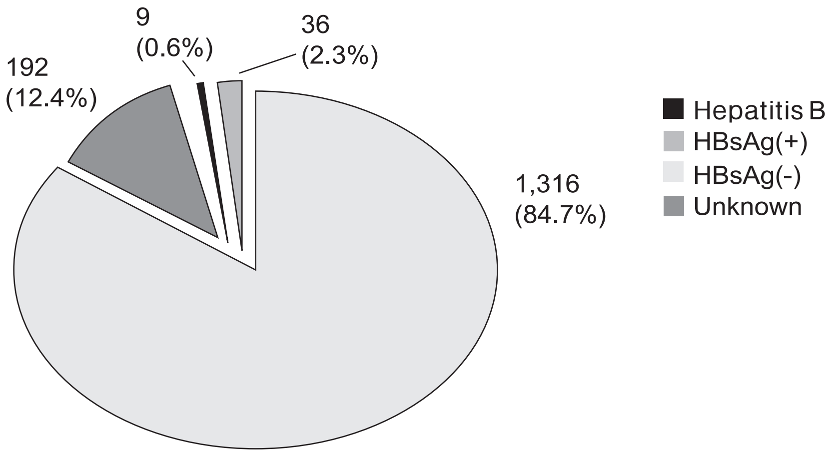
Hepatitis B

Type	Hepatitis B	HBsAg(+)	HBsAg(-)	Unknown	Total
Hemophilia A	9(0.6%)	36(2.3%)	1,316(84.7%)	192(12.4%)	1,553
Hemophilia B	2(0.6%)	7(2.0%)	295(83.1%)	51(14.4%)	355
vWD	0(0.0%)	1(1.1%)	40(43.0%)	52(55.9%)	93
Other	1(1.0%)	1(1.0%)	53(52.0%)	47(46.1%)	102
Total	12(0.6%)	45(2.1%)	1,704(81.0%)	342(16.3%)	2,103

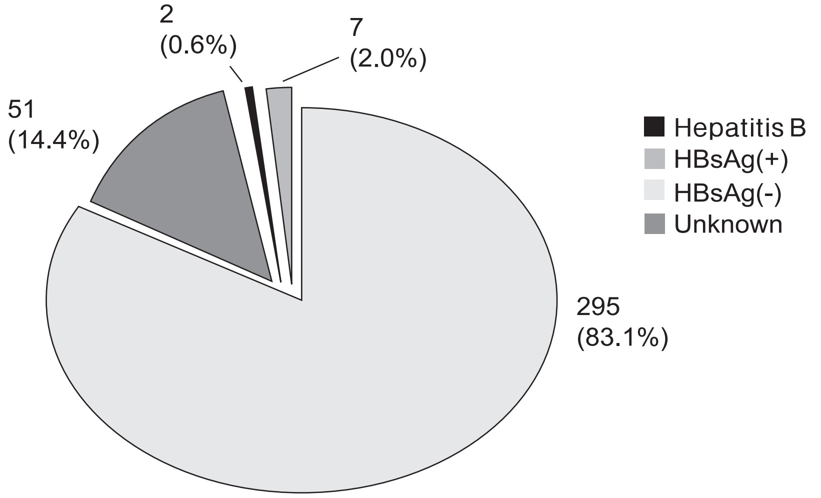
※Hepatitis B : HBsAg (+), ALT ≥50

※HBsAg(+) : HBsAg (+), ALT 〈50

Prevalence of Hepatitis B in Hemophilia A patients



Prevalence of Hepatitis B in Hemophilia B patients



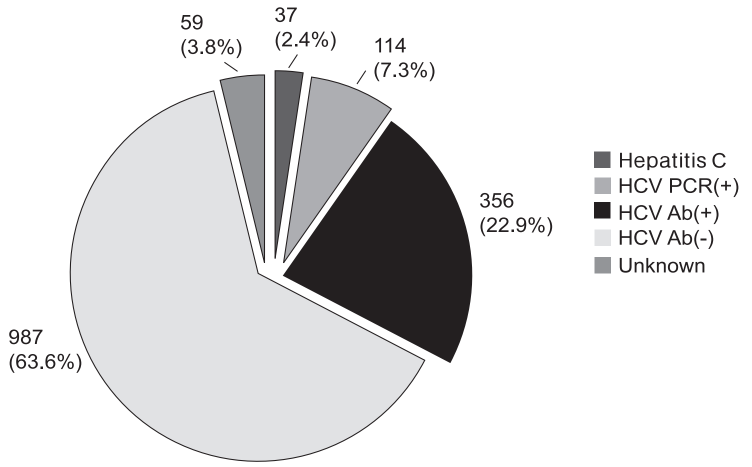
Hepatitis C

Type	Hepatitis C	HCV PCR(+)	HCV Ab(+)	HCV Ab(−)	Unknown	Total
Hemophilia A	37(2.4%)	114(7.3%)	356(22.9%)	987(63.6%)	59(3.8%)	1,553(100.0%)
Hemophilia B	4(1.1%)	15(4.2%)	65(18.3%)	253(71.3%)	18(5.1%)	355(100.0%)
vWD	0(0.0%)	0(0.0%)	1(1.1%)	75(80.6%)	17(18.3%)	93(100.0%)
Other	1(1.0%)	0(0.0%)	4(3.9%)	68(66.7%)	29(28.4%)	102(100.0%)
Total	42(2.0%)	129(6.1%)	426(20.3%)	1,383(65.8%)	123(5.8%)	2,103(100.0%)

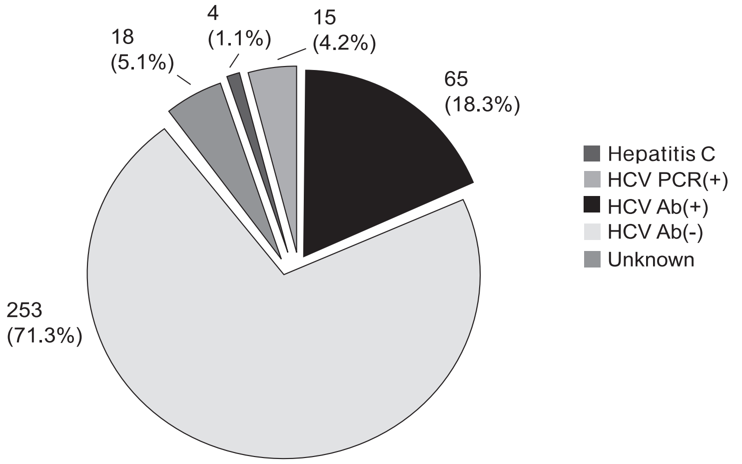
※Hepatitis C : HCV PCR(+), HCV Ab(+), ALT ≥50

※HCV PCR(+) : HCV PCR(+), HCV Ab(+), ALT〈50

Prevalence of Hepatitis C in Hemophilia A patients



Prevalence of Hepatitis C in Hemophilia B patients



Annual Consumption of Factor concentrate in 2011

(Unit : IU)

Type	In KHF Clinics	In Korea	Per 1 Capita
pdFVIII	45,763,000	74,335,500	1.49
pdFIX	2,208,750	3,148,250	0.06
rFVIII	52,636,500	82,113,000	1.64
rFIX	21,823,500	23,499,000	0.47
aPCC	7,508,000	10,105,500	
rFVIIa	124,330	871,280	
pdvWF	3,817,500	3,841,000	

※ Unit is International Units (IU). But rFⅦ's unit is KIU (1,000IU)

※ Consumption data based on each company's sales record in 2011.

※ Korean population is estimated at 50 million according to standard in 2011.

Factor Consumption per Patient in 2011

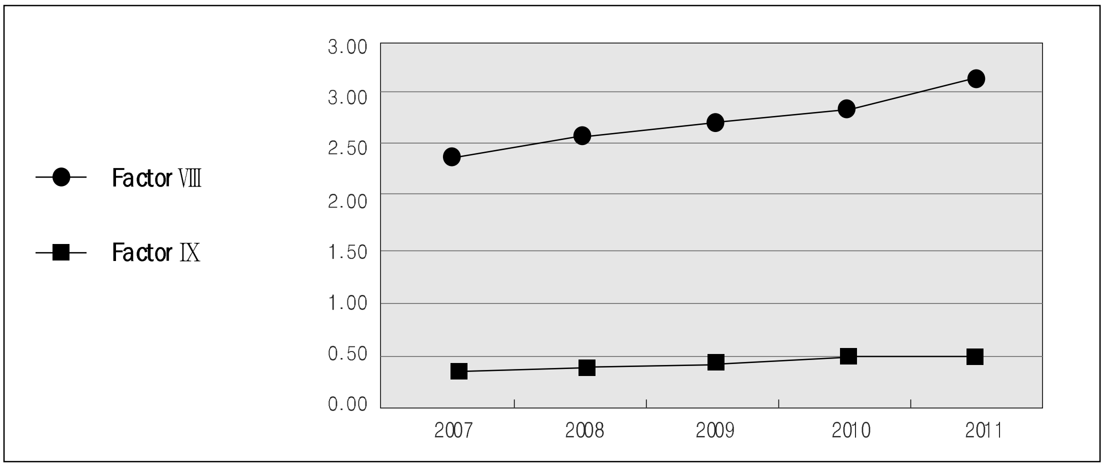
(Unit : IU)

Type	2011			2010	Rate
	No. of Patients	Total Consumption	Per 1 Patient	Per 1 Patient	
FVIII	1,553	156,448,500	100,739.54	91,168.53	↑10.5%
FIX	355	26,647,250	75,062.68	75,926.09	↓1.1%

Factor Consumption Last 5 years

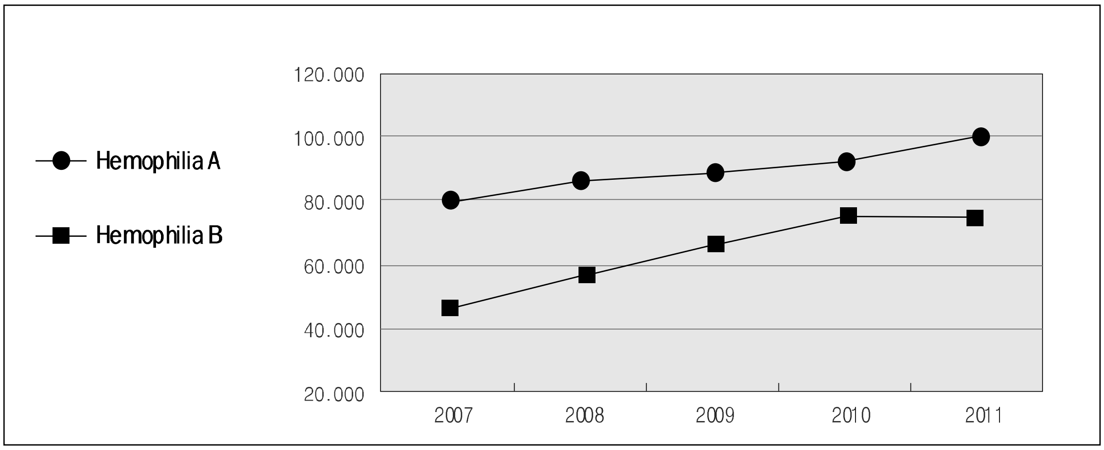
Factor Consumption per 1 Capita Last 5 years

Type	2007	2008	2009	2010	2011
Factor VIII	2.39	2.59	2.70	2.78	3.13
Factor IX	0.31	0.40	0.46	0.52	0.53



Factor Consumption per 1 Patient Last 5 years

Type	2007	2008	2009	2010	2011
Hemophilia A	78,728.38	84,099.66	89,466.82	91,168.53	100,739.54
Hemophilia B	48,181.23	58,634.97	67,347.18	75,926.09	75,062.68



Organization of KHF

Board of Directors
Medicopharmacy Council
Staff members of KHF

Organization of KHF

Board of Directors

The Board of Directors consists of 9 directors and 2 auditors, including the following members: (As of May 1st, 2012.)

△President : Tai Ju Hwang (Emeritus Professor, Dept. of Pediatrics, Chonnam National University)
△Advisors : Il-sup Huh (President of Green Cross Corp.)
Soon-Yong Lee (Director of KHF Busan Clinic)
Myung-Chul Yoo (Vice President of Medical, Kyung Hee University) - served as an advisor and director
Jung-Koo Yoon (Standing Advisor of KHF)
△Directors : Yong-Mook Choi (Standing Director of KHF)
Jong-Ho Song (Executive Director of KHF)
Kun-Soo Lee (Professor, Dept. of Pediatrics, Kyungpook National University Hospital)
Seon-Yang Park (Professor, Dept. of Hematology/Oncology, Seoul National University)
Young-Min Choi (Professor, Dept. of Obstetrics and Gynecology, Seoul National University)
Sang-Gyu Park (Professor, Dept. of Pediatrics, University of Ulsan)
Kang-An Lee (Director of Kang-An Clinic)
△Auditors : Hong-Ryul Ahn (Lawyer at Ahn Hong-Ryul Law Firm)
Sung-Soo Gwon (Senior Researcher at the Korea Accounting Institute)

Medicopharmacy Council

Medicopharmacy Council were established November 2006 to perform works on medical and pharmacy efficiently.

△Chairman : Kun-Soo Lee (Professor of Kyungpook National University)
△Member : Seon-Yang Park (Professor of Seoul National University)
Hwi-Joong Yoon (Professor of Kyung Hee University)
Seung-Ki Choi (Professor of Cha Medical Science University)
Jong-Ho Song (Executive Director of KHF)
Ki-Young Yoo (Director of KHF clinic)

Staff members of KHF

A total of 29 staff members work for the KHF as full-time employees. The KHF consists of the Executive Office, KHF Clinic, KHF Gwangju Clinic and KHF Busan Clinic. As of May 2012, KHF has the following staff members:

△Executive Director : Jong-Ho Song

△Executive Office (FTEs : 8)

- Administration: Seol-Woon Hwang (Associate Director)
  Myung-Hee Lee (Manager)
  Tae-Hyung Gu (Manager)
  Sang-Ho Kim
- Welfare & Planning: Dae-Guen Lee (Vice-Director)
  Hye-Sook Noh (Manager)
  Yun-Jung Kim (Assistant Manager, Social Worker)
  Jong-Wan Woo

△KHF (Seoul) Clinic (FTEs : 10)

- Director: Ki-Young Yoo, M.D.
- Nurses: Sang-Chun Ju (Head Nurse),
  Hye-Ryeon Park
  Jung-Im Kim
- Physical Therapy: Se-Jin Kwon (Vice-Director)
  Jong-Sun Kim (Assistant Manager)
- Clinical Laboratory: Soo-Young Jung (Assistant Manager)
  Jin-Young Choi
- Radiology: Jin-Guk Kim (Assistant Manager)
- Administrating Assistant: Mi-Yeon Yoo (Assistant Manager)

△KHF Gwangju Clinic (FTEs : 4)

- Director : Byung-Ryoung Lee, M.D.
- Nurse : Jeong-Hyun Chae
- Physical Therapist: Yong-In Jin
- Administrating Assistant: So-Yeon Kim

△KHF Busan Clinic (FTEs : 4)

- Director: Soon-Yong Lee, M.D.
- Nurse: Hye-Sook Bae
- Physical Therapist: Jung-Sook Yang
- Nurses' aide: Kwang-Hee Jang

△Homecare Service Team (Local Staff : 4)

- Daegu/Gyeongsangbuk: Young-Ja Kim (Counselor)
- Busan/Gyeongsangnam: Sun-Kyung Kim (Counselor)
- Gwangju/Jeollanam: Eun-Hee Song (Counselor)
- Jeollabuk: Sang-Jin Park (Counselor)

Korea Hemophilia Foundation
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