2009 Annual Report

Korea Hemophilia Foundation

Korea Hemophilia Foundation
한국혈우재단

2009 Annual Report

Published by Korea Hemophilia Foundation
1628-26, Seocho-Dong, Seocho-Gu, Seoul, 137-879 Rep. of Korea
Tel : +82-2-3473-6100 Fax : +82-2-3473-6644
E-mail : kohem@kohem.org web site : www.kohem.org
Editoril supervision : Priscilla Jwa

CONTENTS

1. President's message · 04

2. KHF Activities in 2009
- Overview · 08
- Major Activities · 10
- KHF Clinics · 20

3. Hemophilia Status in 2009
- Status as Type of Disease · 30
- Status of Registration by Year · 31
- Status as Region · 32
- Age Distribution · 33
- Status of Women's Registration · 34
- Status as Severity · 35
- Monthly Bleeding Frequency by Type, Severity · 35
- Status of Hemathrosis · 36
- Status of Hemathrosis as Severity · 36
- Status of Disabilities · 37
- Self-injection Capacity · 37
- Status of Inhibitor (Antibody) · 38
- Status of Hepatitis B · 39
- Status of Hepatitis C · 40
- Annual Consumption of Factor Concentrate · 41
- Factor Consumption recent 5 years · 42

4. Organization of KHF
- Board of Directors · 44
- Medicopharmacy Council · 44
- Staffs of KHF · 44

Korea Hemophilia Foundation

President’s Message

Thank you for all your efforts to improve our treatment environments for hemophilia patients as well as various businesses of KHF, including publishing of the annual report of Korea Hemophilia Foundation (KHF).

I think all of you might already know well that KHF aims to improve the quality of life for the hemophilia patients in Korea.

Moreover, if there has not been the noble will of the late Dr. Young-Sup Huh who established this foundation despite the difficult times, today’s governmental supports and treatment environments that we have accomplished must have been still far-off.

Once again, I’d like to express my gratitude and condolences to the late Chairman, Dr. Young-Sup Huh, through this annual report.

As many people have already known through several press releases, the annual usage amount of clotting factors for hemophilia patients in Korea reaches 82,683IU for hemophilia A. This ranks Korea at the 8th highest in the world, and 58,635IU for hemophilia B, ranking the 9th highest usage respectively.

The consumption of clotting factors per capita has also been increased to 46.5% and 44.4% each, compared to year 2005.

As there is no burden for individual hemophilia patients to pay for the treatment through support projects for patients having rare and incurable disease, the patients in Korea are under better treatment environments than those of every other nation.

There are still few patients who can’t get benefits from governmental subsidy.

Even so, individual cost is only 3,000,000 Won per year and KHF is trying to minimize the individual costs by sharing 50% thereof.

Despite such conditions, there are still numerous point-outs that hemophilia treatment environment in Korea needs much more improvement.

For immune tolerance therapy and prophylaxis which are common in advanced countries, restrictions such as limiting the number of monthly treatments and ages for medication of recombination products have to be removed.

KHF, the social welfare foundation, will celebrate it's 20th anniversary in 2011.

If it was the growing period for the foundation up to now, safe and stable activities of the foundation should be expanded from next year.

We will continue to perform to overcome the limit of our capabilities and prestige raised at home and abroad through the last 19-year of activities, and will try to settle the problems down in a proactive manner.

I'm sure that many patients, their family and medical teams will work with us to make such efforts possible.

I have placed great emphasis on "one step up" to our foundation associates after my inauguration as the president.

It is to that effect that we make patients' conditions and hemophilia treatment environments in Korea to improve step by step.

For patients who are not mobile due to the joint contracture, we can help them to be more mobilized using a wheel chair, crutches, and by themselves step by step through surgical operation, rehabilitation and treatments.

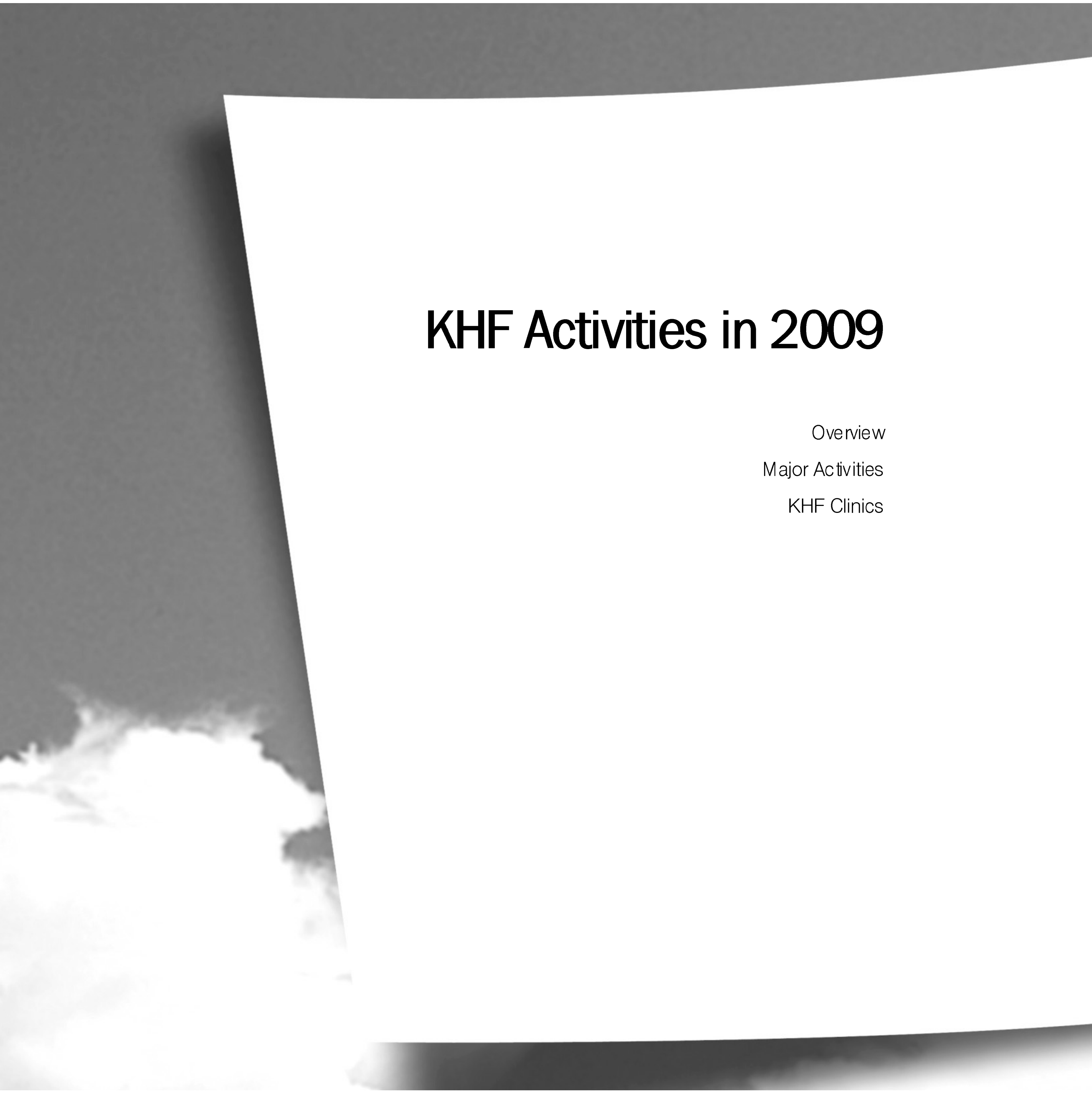
Domestic hemophilia treatment environments might be much the same.

If we agree to what are the most impending issues, then it won't be so difficult to deal with those issues one by one.

I'm confident that, through such kind of efforts, we can overcome difficulties and finally achieve a vast mountain such as the complete recovery of hemophilia which everyone longs and dreams about.

I wish all the happiness be with you and your family.

Yong-Mook Choi, M.D., F.A.A.P.
President
Korea Hemophilia Foundation



KHF Activities in 2009

Overview
Major Activities
KHF Clinics

A year of loss in hemophilia society

-Overview 2009

▲ 2009 Staff's workshop (17. Jan. 2009)

The total number of hemophilia and bleeding disorder patients registered in Korea Hemophilia Foundation(KHF) is 2,009 in December, 31st, 2009(Detail statistics in page 00~00). Each type consists of Hemophilia A (1,507 patients, 75%), Hemophilia B (337 patients, 16.8%), von Willebrand Disease(vWD, 86 patients, 4.3%), and other bleeding

▲▲ New year's opening ceremony (02. Jan. 2009)
▲ 2009 Staff's workshop (17. Jan. 2009)

disorders such as Factor I Deficiency (59 patients , 2.9%).

In 2009, newly registered patients were 63 ; Hemophilia A was the biggest number with 41 patients (65.1%) and the others were Hemophilia B with 12 patients (19%), von Willebrand Disease(vWD) with 5 patients (7.9%), other Factor Deficiencies with 4 patients (6.4%), and 1 unknown (1.6%).

The hemophilia patients and their families were educated in relatively small groups such as local branch meetings or home visiting education. In 2009, 'Hemophilia Seminar', educating hemophilia patients and their families was held for the first time after the establishment of the foundation. 470 people participated in 'Hemophilia Seminar' in May and October. Hemophilia patients treated in KHF's clinics in Seoul, Busan, and Gwangju were total 1,706; Seoul clinic with 1,352 patients (21,636 cases), Busan clinic with 213 patients (3,949 cases), and Gwangju clinic with 141 patients (4,172 cases). This number is 84.9% of 2,009, total patients and in 2009, for a year, patients got treatments approximately 17.4 times per person.

Most of all, in 2009, hemophilia society learned the importance of developing medications domestically and lost a great person who has devoted his life to producing domestic medications and improving medical environment and quality of life for hemophilia patients.

First, the supply of Novo Seven, Recombinant Factor VIIa concentrate for the hemophilia inhibitors and VII factor deficiency patients was discontinued for 3 months.

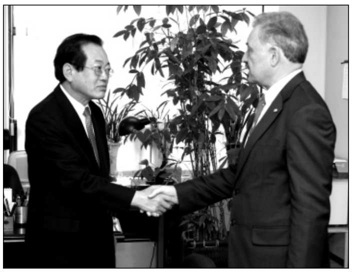
Novo Nordisk decreased the price of Novo Seven to 46.1% as extending the drug reimbursement from the second-line medication to the first-line medication in June, 2008. However, Novo Nordisk Inc. claimed to increase the price of medicine due to loss by rise in exchange rate and discontinued the supply of medication from May, 2009.

Hemophilia patients with inhibitors might treat with Activated Prothrombin Complex Concentrate (aPCC). However, other patients such as other types of inhibitors or Factor VII Deficiency patients were not able to have medication therapy, so they had to wait for three months.

Finally, Novo Nordisk Inc. agreed with Ministry of Health & Welfare to increase the price to average 35%, supply about $ 2 million dollars of medicines as free of charge, and resume the supply of the medicines from August, 8th.

Dr. Young-Sup Huh who established Korea Hemophilia Foundation (KHF), was the President until 1998. He helped to improve welfare of Korean hemophilia patients and passed away in November 15th, 2009, with the age of 69. The late Dr. Huh helped hemophilia patients who could not afford to pay for the treatment and did not get any help despite the financial problem he had for himself. The late Dr. Huh's love and belief in volunteer work will last with KHF forever. (The profile of the late Dr. Huh and memorial writings - page 22)

▲ Board of directors meeting (24. Feb. 2009)



▲Mr. Ceferion Valdez Peralta, ambassador of Paraguay visited KHF (13. Mar. 2009)

▲ New patients' family education program (17. Apr. 2009)

Major activities in 2009

Korea Hemophilia Foundation set the goal as establishing treatment system by medical information of network between affiliated clinics and improving quality of therapy by visiting treatment using Homecare Welfare Service Team. KHF also focused on the followings ; building up hemophilia patient treatment system, improving services on neglected class of people, supporting patient education and information, and studying on hemophilia research and projects. KHF used about 5 billion won for these services in 2009. The results are reported below.

1. Patient support project

In the article of association, the purpose of KHF describes "The KHF will maintain a close cooperative relationship with the WFH in the future and make efforts for future hemophilia projects in Korea. Furthermore, living up to the motto of the WFH, it will actively cooperate with them in the execution of various projects, thereby giving even greater hope to patients and rendering more effective assistance to them". That is, all the projects belong to the support of treatment and rehabilitation of hemophilia patients. After being established, KHF supported 20% of deductable of Factor concentrates until 2000. However, government's medical expense support for rare & incurable disease from 2001 helped 20% of uncovered health insurance, hemophilia patients financial issues and medical environments got improved. Therefore, KHF founds the ways to help hemophilia patients directly.

△ **Support government's medical expense dropouts :** Government's medical expense support for rare & incurable disease excludes people who have more incomes than average. KHF supports 50% of deductible(maximum $2,000 per year) for the dropouts to provide treatment at least. In 2009, 177 patients were supported with $24,000. 12% of applications and 23.1% of support expenses were increased compared to 2008.

△ **Non-formulary support :** Although patients are covered with government's medical expense support for rare & incurable disease, there is non-formulary expense, not covered by national health insurance and covered patients or low-income patients have hard time to have operations or consistent therapy due to non-formulary expense. KHF supports total non-formulary medical expenses and MRI procedure and high non-formulary examination fee for outpatients by $3,000 excluding dues for superior hospital rooms. In 2009, 60 patients, increased 9.1% compared to the last year were provided $68,000.

△ **Chronic Hepatitis patients medical expense support :** Hepatitis C are spreaded from contact of infected blood and causes inflammation in liver by virus. It is more likely to be infected when the patient

> "Korea Hemophilia Foundation set the goal as establishing treatment system by medical information of network between affiliated clinics and improving quality of therapy by visiting treatment using Homecare Welfare Service Team."

▲ New patients' family education program (17. Apr. 2009)

▲ New patients' family education program (17. Apr. 2009) got blood transfusion before 1992. In Korea, 591 patients, 32% of hemophilia A and B (1,884 patients) were infected to HCV Ab(+), 141 patients of HCV PCR(+), 48 patients(2.6%) of hepatitis C. KHF has been supporting medical expenses for both hemophilia and hepatitis C patients from 2002 and KHF affiliated clinics started to treat hepatitis C directly and supported medical expenses. It is fortunate get a cover on hepatitis C medications. In 2009, $21,000 were supported for 82 patients and 703 patients were covered with $363,000 for 8 years. 〈Refer to the table〉

Year	Amount	No. of Patients
2002	14,148,360-	20
2003	36,000,000-	36
2004	14,000,000-	13
2005	5,000,000-	7
2006	13,000,000-	19
2007	151,000,000-	423
2008	109,000,000-	103
2009	21,000,000-	82
Total	363,148,360-	703

△ **Employment education support :** Hemophilia patients over 30 years old, who were teenagers before KHF was established have physical disability caused by frequent bleeding. Also, hemophilia patients are exempt from the obligation to serve in the military and disadvantaged by being known about their disability on getting a job. KHF helps them to have employment education and support education expense for low-income patients. In 2009, 7 patients were supported with $8,000.

△ **Emergency special aid :** The difference between normal person and hemophilia patient is the possibility of bleeding without exogenous impact. This bleeding is called 'natural bleeding.' Especially, bleedings in brain, intestines, and throat may be dangerous and need to be treated immediately. However, in case of lower-income patients, it is hard for them to get medical treatment in emergency situation. KHF started Emergency special aid for the poor patients to give them a relief by supporting medical expense and extra finances. This

KHF used about 5 million dollars for supporting patient education and information, and studying on hemophilia research and projects in 2009

① ②
③
⑤ ④

① Support for World Hemophilia Day event of Kohem Association (19. May. 2009)
②~⑤ 2009 Hemophilia Seminar (09. May. 2009)

system covers $2000 per person a year for transport fee and unavoidable superior hospital room charge in emergency situation. 2 patients were covered with $1,100.

△ **Non-formulary test fee support :** Test of hemophilia A and B are covered, however, test of von Willebrand Disease and genetic studies are not covered. KHF supports test fee of non-formulary, 136 patients for test of genes were covered with $15,000, other tests of coagulation factors deficiency disease were covered with $1,700 and the total was $16,700. Although the number of test of genes were increased to 66 patients (94.3%), the support expense was only increased to 41.5%. This is because patients themselves or wanted patients only got test and spendings on medical expense were decreased.

△ **Swim training support :** Buoyancy during swimming helps to decrease pressure from body weight on joints and hemophilia patients and bleeding disorder patients are recommended to swim. KHF opened swimming classes for hemophilia patients and supported swimming training fee as a trial project in 2008. In 2009, it was converted to a regular project and 90% of training fee was covered for the upper receiver and $70/mo as a standard of 50% for 5 months for health insurance covered patients were supported. Total 97 patients were supported with $10,000.

△ **Other medical expenses support :** KHF affiliated clinics (Seoul, Gwangju, Busan) supports immunizations and 33.3% was increased the amount of $2,400 compared to last year in 2009.

△ **Young patients new year's gift :** It is normal to give gifts to people for Christmas and new year in Korea these days. KHF have been sending gifts to young patients at the end of year. In 2009, 296 patients of 4~12 years old were received gifts from KHF. Total expense was $5,000.

2. Patients organization support project

In January, 1998, Young Men's Kohem Association was extended to Kohem Association as a hemophilia organization. Also in 2006, Chung Shim Association, Hemophilia organization from Honam area was established independently. Chung Shim Association helps on education , children's day events, summer camp and etc and KHF supports Chung Shim Association as a co-business organization.

△ **Patients shelter support :** Patients who live in rural area have hard time to get to hemophilia assigned hospitals in city. KHF opened and supported patient shelters in Busan, Daejoen, and Daegu to commute hospitals and share information. Now, only one patient shelter is running in Daegu and 353 patients used this shelter in 2009. The amount of support is $10,000 as a rental deposit, $3,900 as a maintenance fee and the total is $13,900. Also, KHF tries to open a patient shelter in hemophilia assigned hospital (Jeonju Jesus Hospital) in Jeonju continuously.

△ **Patient organization trust expenses support :** Kohem Association runs Kohem's house and transfer of operated patients and Chung Shim Association runs business on improvement of treatment in Gwangju clinic and welfare for local hemophilia patients as trusts. KHF supported $170,000 to Kohem Association, $22,000 to Chung Shim Association, $8,400 to moved Kohem's house and the total was $190,000.

△ **Patients organization event expenses support :** Summer camp held by patients' organization is the biggest event during a year and many hemophilia children patients are waiting for this event. KHF supported $30,000 to Kohem Association's summer camp, $28,000 to Chung Shim Association's summer camp, $6,000 to Chung Shim Association's children's day events (ocean experience) and the total was $64,000. Children's day events of Kohem Association were included in trust fund.

▲ Multi-culture families meeting (26. Sep. 2009)

3. Homecare Welfare Service Team

Hemophilia patients can have normal lives after consistent therapy and deficiency factor treatment. However, patients themselves and their family have hard times to cope. Also, as a chronic disease, one of family members can take medicine for their patients and support from family is important. Especially patients over 30~40 years old need to be supported frequent visits and making them relieved. Homecare Welfare Service Team by KHF consists of one of social welfare worker and five counselors who were patients and patients' family in Seoul, Gyeongbuk, Gyeongnam, Jeonbuk, and Jeonnam. In 2009, 827 people had 1,369 times of counseling and this number is 60% of registered patients. Counseling in community office, health center, social department in hospitals, and nurse's office in schools was 64. Social adjustment programs for patients and families were run with 450 people, 22 times. The major organization programs are below.

△ **New patients' family education program** : 5 times / 129 people (Seoul and Busan 2 times each, Gwangju

▲ New patients' family education program (07. Nov. 2009)

▲ Volunteer for persimmon harvesting (08. Nov. 2009)

once)

△ **Experience program :** Military experience, multicultural family experience, farm experience 3 times / 74 people

△ **Swimming class** : 6 times / 161 people

△ **Local patient immunization and physical therapy visiting education** : 3 times / 48 people

△ **Small group meetings** : 5 times / 38 people

△ **Patient organization events support** : 11 times

Also, patients who are having difficulties in landing jobs are supported by job link program. However, no patient actually got a job from this program because of social unemployment rate and applications on competitive jobs in 2009.

4. Study and research support

Although hemophilia treatment environment got better, there are only 16 specialized hemophilia treatment centers (hospitals) and specialized doctors on hemophilia are only 30. Especially the more hospital treat hemophilia patients, the more the amount of loss

Result of monthly major counseling

Month	Major counseling patients and contents	Total No. of patients	Counseled patients
January February	New registered patients in 2007~2008 - New patients program will survey, hemophilia acceptance scale	124	93
March April	Elementary school student patients School and family management program	245	220
May June	Low income family patients - Hemophilia management, financial support system	219	183
July August	Patients over 40 years old - Hemophilia management, current therapy report	221	181
September Octobe	Non-counseled patients - Hemophilia management, current report	271	213
Novembe	New registered patients after July, 2008	77	71
December	Non-counseled patients and missing contact patients (Jeonnambuk, Gyeongnambuk)	131	89
Total		1,288	1,047

is getting bigger due to current medical system, so it is hard to spread hemophilia medical facilities throughout the country. Moreover, although home-therapy was allowed and limited factor deficiency therapy is recommended, home education on hemophilia is needed continuously. KHF studies a lot about hemophilia and provides new hemophilia medical information to the doctors. Also, KHF supports programs on providing information to patients and their families from beginning of KHF.

▲ 2009 East Asia Hemophilia Forum in Japan (06. Jun. 2009)

△ **Hosting hemophilia seminar** : To provide accurate information on hemophilia management to patients and their families, hemophilia seminar was hold in May and October, 2009 and total of 470 people participated. In May 9TH, The first Hemophilia seminar was held in Kintex, Ilsan and introduced different bleeding situations and management, how to make joints healthy, hemophilia and sports, factor deficiency therapy, Australian history of current news in hemophilia therapy, hemophilia emergency network of Taiwan Samgunchong hospital hemophilia clinic, and ' Factor, Stop bothering me!.' Especially, Canada, Australia, Taiwan visitors participated and it was a good chance for us to know other countries' systems. In October 10th, the 2nd hemophilia seminar was discussed on 'Learn from patients who had surgery!', orthopedic problems and therapy of hemophilia patients, stress and depression - how do we deal with?, rehabilitation after hemophilia surgery, orthopedic problems such as Tai Chi Exercise in Seoul Metro Education Center. The total budget was $56,000.

△ **2009 East Asia Hemophilia Forum participation** : East Asia Hemophilia Forum participation was established by KHF as a leader and Japanese, Taiwanese, Chinese, and Korean doctors shared their information and experience. In

November, 2008, after the first forum in Coex, Seoul, the second forum was held in Kitakyushu, Japen, from June 6th to 7th, 2009. KHF supported 11 medical providers and 11 offices to participate. Total budget was $16,000.

△ **Hosting 2009 Hemophilia Symposium** : Hemophilia Symposium was held from June 13th to 14th in Haevichi Hotel, Jeju to support Korean hemophilia medical providers, department officers, and foundation officers, total 60 people to provide information. In 2009, Hemophilia Symposium introduced factor deficiency therapy using gene recombinants medicine, coagulation factor therapy, current treatment of Korean hemophilia patients with hepatitis C, effects of visiting treatment, and discussion about Korean hemophilia treatment. Total budget was $54,000.

△ **Other conference participation**

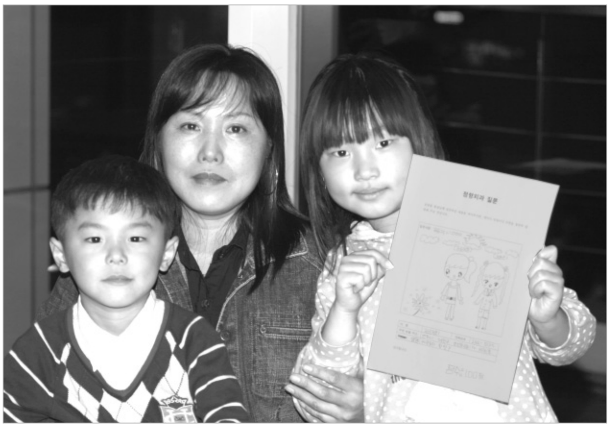
- Asia Pacific Hemophilia Conference : 5/22 ~ 5/23, Shanghai, China, 7 participants
- ISTH 2009 : 7/11~7/16, Boston, USA, 2 participants
- 2009 EHC conference : 9/11~9/13, Vilnius, Lithuania, 8 participants
- Global Nurse Symposium : 4/28~4/30, Vienna, Austria, 2 participants

△ **Hemophilia journal subscription support** : To support the newest information, 22 Korean hemophilia medical providers and 4 organization officers subscribed 'Hemophilia journal', formal academic journal. Total budget was $8,400.

△ **Foreign medical providers invitation** : Dr. Ibrahim Ulman from Turkey where a lot of circumcision is performed traditionally was invited to learn circumcision of hemophilia patients. It was a conference about establishing standard of circumcision of hemophilia patients. The total budget was $3,300.

△ **Hemophilia study accepting and budget support** : KHF was accepting study subject and selected 2 subjects were supported $20,000 each from 2001 (3 subjects/year from 2001 to 2005). In 2009, Dr. Myung-Chul Yoo, a chair-professor from Kyung Hee university was supported finance on a project ' Effect of self-management Tai Chi exercise adapted to hemophilia patients to life quality.' 21 subjects studies were supported financially in 2001, 17 studies were finished successfully, 2 studies were stopped, and 2 studies are currently ongoing. The total budget was $349,144 from 2001 to 2009.

▲ 2nd Hemophilia Seminar (10.Oct.2009)

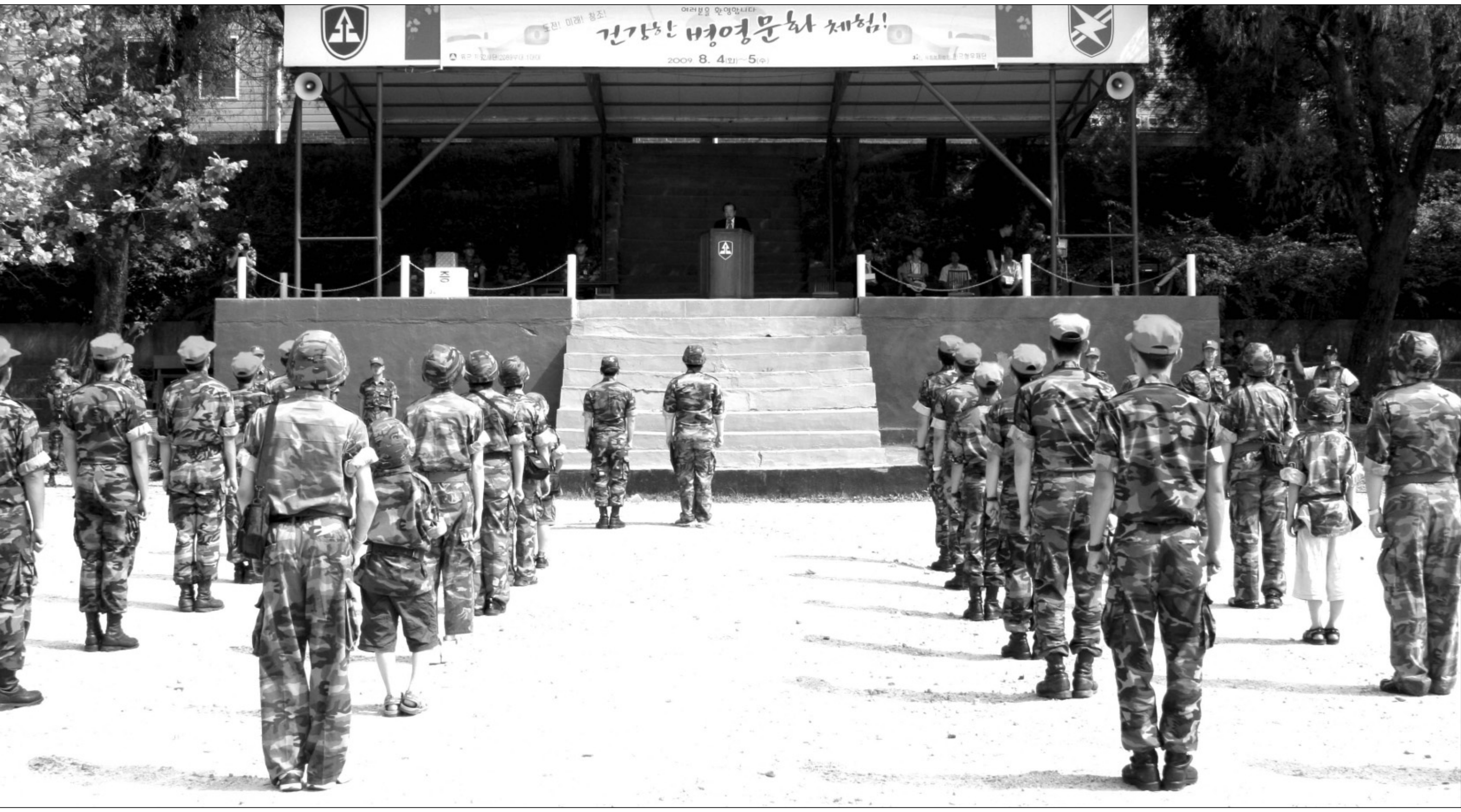


▲ 2nd Hemophilia Seminar (10.Oct.2009)

△ **Medicopharmacy council activities** : KHF opened Medicopharmacy council to perform works on medical and pharmacy efficiently and to review the followings : Studies on hemophilia research, improvement of medical equipment and facilities, selection and deletion of medicines, efficacy and side effects of medicine, and consideration from a president. In 2009, 4 times of Medicopharmacy council was held.

5. Promoting and other projects

It has been 18 years since KHF was established. However, there are still much prejudice against hemophilia patients. To overcome these prejudice, we should continuously conduct promotion to prevent



'discrimination of hemophilia patients externally or among themselves.' KHF is the only place that registration and management of hemophilia patients (transferred of work from Health Society department in March, 1991) are took charge of and the statistics on different hemophilia is another important work.

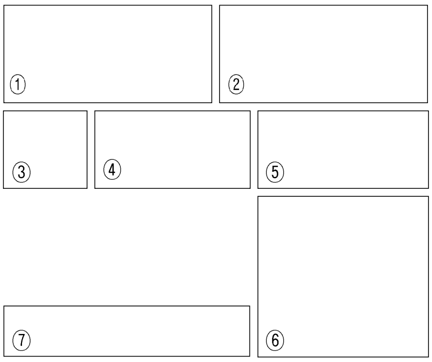
△ **By-monthly magazine 'Kohem' publication** : 'Kohem' is a by-monthly magazine and the 100th edition was published in 2008. In 2009, the 105th to 110th editions were published and 3,100 copies were sent to hemophilia patients, medical facilities, and organizations. The total budget is $25,000.

△ **Annual report publication** : Hemophilia White book shows KHF's projects at a glance and is published in Korean in every odd-number year and in English in even-number years. In 2009, 300 of annual reports were published to be sent to medical facilities and organizations.

△ **Education Booklet publication** : When parents do not know about the management on hemophilia due to lack of information on 'What hemophilia is and its management.' Also, other education booklets are needed for other types of bleeding disorder patients. For this, in 2009, 'All about von Willebrand Disease' booklet from Canada Hemophilia Association was translated to Korean, 300 copies were published, and published additional of 'Guideline for hemophilia treatment (200 copies)', 'Treatment manual for Hemophilia and other bleeding disorder (200 copies)', and 'Rehabilitation exercise for hemophilia patients (400 copies)', were published before. Also, 'Psychosocial Care for People with Hemophilia' and 'Pregnancy in Women with Inherited Bleeding Disorders' in TOH(Treatment of Hemophilia) series from World Federation of Hemophilia were translated to Korean as PDF files and those PDF files were published and posted on homepage of KHF. The total budget on publications of education booklet was $5,000.

△ **Other activities**

- World Faderation of Hemophilia membership fee : $2,000
- KHF homepage management.
- Short Message service : Offering information about hospital reservation including anniversary congratulations and events news to 958 people, SMS subscribers with 12,462 messages.



① Self-injection training in KHF clinic (23.Jun.2009)
② New patients' family education program in Busan clinic (11.Jul.2009)
③~⑥ 2009 Military camp (04. Aug.2009)
⑦ Swimming class in Summer vacation (22.Aug.2009)

KHF clinics –2009

Hemophilia cooperated hospitals with KHF was only Severance Hospital, Sinchon, Chonnam National University Hospital, and Inje University Baik Hospital, Busan in 1990, in the beginning period of KHF. It was not enough to treat patients. Board of directors who prepared to establish KHF, decided to open KHF affiliated clinics to help hemophilia patients convenient and special treatment. KHF clinic (Seoul clinic) were established in February 11th, 1991 with KHF, Gwangju clinic opened in 2006, and Busan clinic opened in 2007.

1. KHF Clinic in Seoul business report

1,352 patients a year, 21,636 in total were treated in KHF clinic in 2009. This number is 67.3% of registered patients. Office days were 302 days and 72 patients a day had a treatment averagely.

Every Tuesday, office hour was opened until 8:30 pm and 282 patients (120 actual patients) were treated for 48 times. 4,862 patients (419 actual patients) were treated with physical therapy, and this number is 5.5% and 5.8% each increased compared to the earlier year. 625 patients (54 actual patients) used hydrotherapy which started in December, 2008 for 160 days. Clinical pathologic test was performed in total of 33,066 times including 10,163 general blood tests, 11,936 general chemical tests, 4,047 immunology serum tests, and 4,699 blood coagulation test. Gene test was performed in total of 285 times including 4 genetic tests, 86 inversion tests, 12 (actually patients) FVIII Sequencing tests, 7 (actually patients) FIX Sequencing tests, and 6 fetus pre-tests. Radiation test was performed in 2,915 times total to 713 patients a year including 24 hearing tests, 18 ECG test, 56 ultrasonic tests, and other tests for 249 patients. Hepatitis C treatment in KHF clinics was performed to 114 patients, 74 patients fully recovered and 25 patients with treatment ongoing. Treatment failure was reported for 7 patients and stopping treatment was for 8 patients. Visiting treatment for physically disabled patients was performed 34 times to

▲ Gene analysis & prenatal test seminar in Busan clinic (28. Nov. 2009)

▲ Swimming class in Summer vacation (22. Aug. 2009)

18 patients who had 65 times of visiting treatment sessions.

Orthopedic checkup cooperating with Hemophilia operation center, Kyung Hee University East West Neo Medical Center were performed 9 times and 139 patients had tests. During last year, the number of patients who had surgeries from East West Neo Medical Center and Kyung Hee University Medical Center were each 74 (80 operations) and 30 (32 operations), in total of 104 patients (112 operations).

35 Hemophilia patients were educated on self-injection (11 times), Daegu local visiting education was performed twice for 19 patients, Gangwon local visiting education was performed once for 22 patients, surgery patients' group met once for 25 patients and 66 people participated 4 times.

2. KHF Gwangju Clinic business report

KHF Gwangju Clinic had 4,172 times of treatment. Actual patients were 141 and average 15.4 patients a day. 1,451 patients had physical therapy and 17 times for 28 patients had visiting treatment and hemophilia management education. 9 patients joined in an exercise education to learn about managements before and after the surgery, 15 patients had 10 times of self-injection education, and 5 patients were able to self-inject in KHF Gwangju clinic

3. KHF Busan Clinic business report

KHF Busan Clinic had 3,949 times of treatment. Actual patients were 213 and averagely 14.4 patients a day. 1,402 patients had physical therapy and 10 patients had hepatitis C therapy resulted in 2 full recovery and 5 ongoing treatment patients.

36 patients joined in 2 exercise educations to learn about joints damages and therapy, 11 patients had injection education 7 times, and 10 people (6 patients and guardian) were able to self-inject in KHF Busan clinic

Rest in Peace
the late Dr. Young-Sup Hur

Profile of the late Dr. Young-Sup Hur

Memorial Writings

Yong-Mook Choi / President of KHF

Mark W. Skinner / President of WFH

Profile of the KHF founder, the late Young-sup Huh

1941-Born in Gae-pung, Gyeonggi-do
1960-Graduated from Gyeonggi High School
1964-Graduated from Seoul National University College of Engineering, Korea
1968-Graduated from RWTH Aachen University, Germany (Obtained Diplom Ing.)
1970-Dropped out from (Physical Metallurgy), RWTH Aachen University, Germany
2001-Obtained Honorary Doctor of Engineering Degree, Hanyang University, Korea
2002-Obtained Honorary Senator (Ehrensenator), RWTH Aachen University, Germany
1970-Entered Green Cross (Department manager)
1980-President, Green Cross
1990-Established Korea Hemophilia Foundation (KHF)
1991~998-1st ~3rd president, Korea Hemophilia Foundation (KHF)
1992~2009-Chairman, Green Cross
1984~2009-Chairman, Mogam Biotechnology Research Institute
1987~1994-Chairman, The Korea Biotechnology Research Association
1994~1997-1st president, The Korea Biotechnology Industry Organization
1997~1999-16th president, Korean Pharmaceutical Manufacturers Association
2000~2009-President, Korean-German Society
2001~2009-Vice president, The Federation of Korean Industries
2003~2008-4th president, Korea Industrial Technology Association
2005~2008-Chairman, Korea Support Committee for the International Vaccine Institute
2007~2009-Chairman, Korean-German Chamber of Commerce and Industry
1982-Awarded Tin Tower Order of Industrial Service Merit
1984-Awarded Silver Tower Order of Industrial Service Merit
1992-Awarded Order of Civil Merit Moran Medal
2002-The 2nd Korea’ s best CEO Award
2005-Awarded The Cross of the Order of Merit of the Federal Republic of Germany
2008-The 22nd Inchon Memorial Award
2009-Awarded Order of Science and Technology Merit Changjo Medal

Hope keep watch us from the heaven

Yong-Mook Choi
<President of KHF>

As I try to write a memorial writing, memories with the late Mr. Huh come to my mind.

A long time ago, when we wore uniform of Daejeon Middle School, you were the senior and led the whole school perfectly as the commander of the Student National Defense Corps and president of the student council; these reminded me of your maturity.

Last fall, even though you were sick, you expressed yourself clearly when you won Inchon Memorial Award. I cannot forget that moment and I still feel like you would come through the door, saying " I hope you keep up the good work".

I am very sad and cannot believe that you were buried in Green Cross yard. I feel really bad why God left us and took you away from us.

I have been working for ten years as a dirctor of Korea Hemophilia Foundation where you established with meaningful reasons although it was hard to build it up as a business person. When you talked about planning on establishing of Korea Hemophilia Foundation, we were not sure about how long this foundation would last and be able to be supported. We realized that the meaning of helping patients was a big sacrifice for the hemophilia treatments due to no support before and poor environments. We were concerned a lot because it needed sacrifice against pursuit of profit and properties of business.

However, you founded Korea Hemophilia Foundation with your passion and positive drive, opened clinics only for hemophilia patients who struggled financially and were not able to be treated, and made dreams came true. So far, it was hard to treat the hemophilia patients due to the prejudice.

Although you were busy, you participated in summer camp. You also participated in Hemophilia World Congress several times to encourage staffs and all the Korean attendances. You always expressed that you were not doing it for any benefit but for others and while we were working with you, we began to stop worrying about what you had been doing and doctors and patients including us started to trust you. KHF clinics have been improving for the last 20 years and amazed the world with great facilities and therapy systems. We made hemophilia patients to live normal life after proper treatments like developed centuries do.

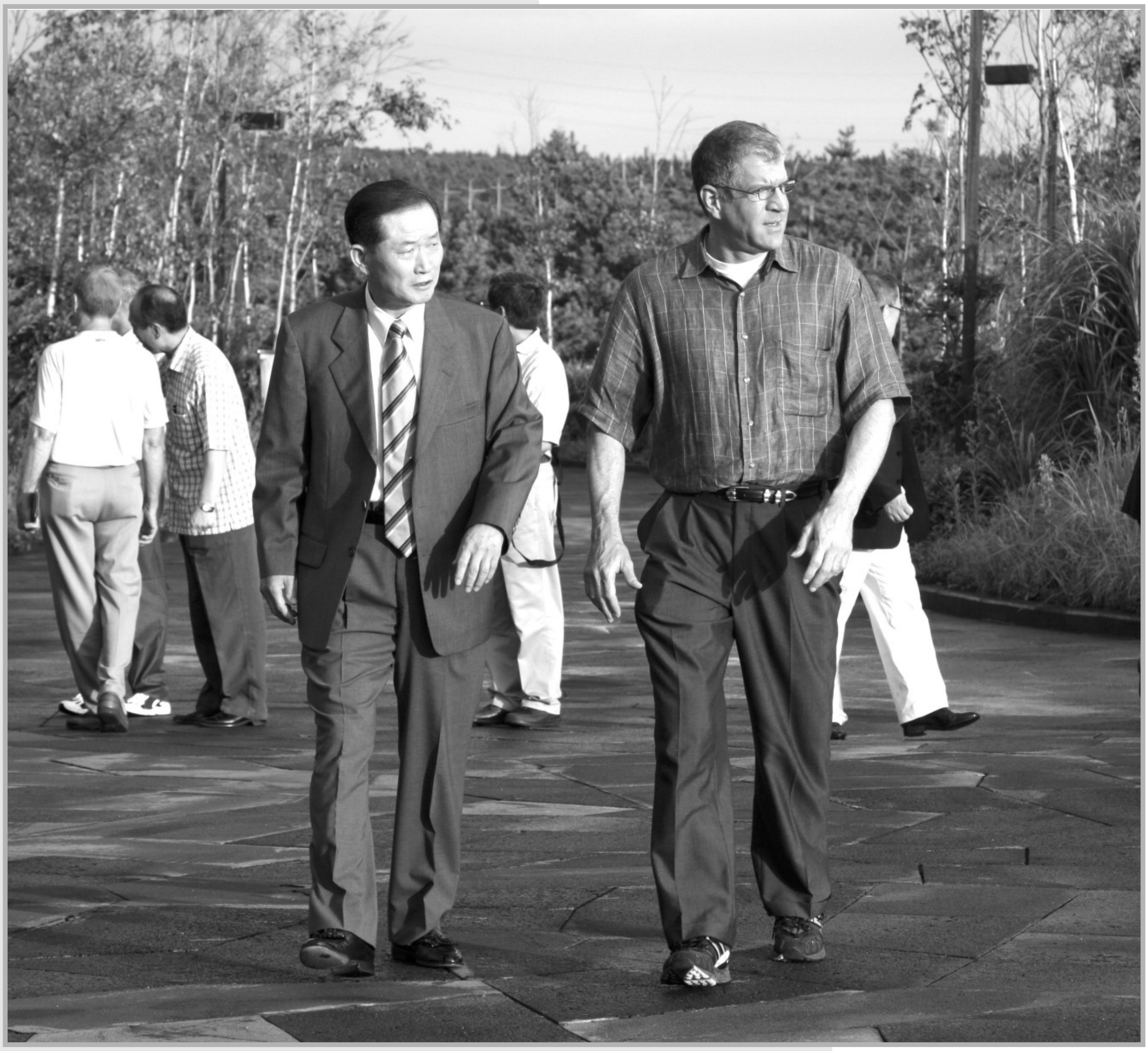
We never gave you anything in return and we are sorry that you left alone like this. We would like to say how much we appreciated what you did, but you are not here with us anymore. It was totally your decision to rest in Green Cross yard rather than in a luxurious grave. You gave us a lesson to think about and looking back our lives. When we think back, we will go back to dust but we are struggling with desires and conflicts.

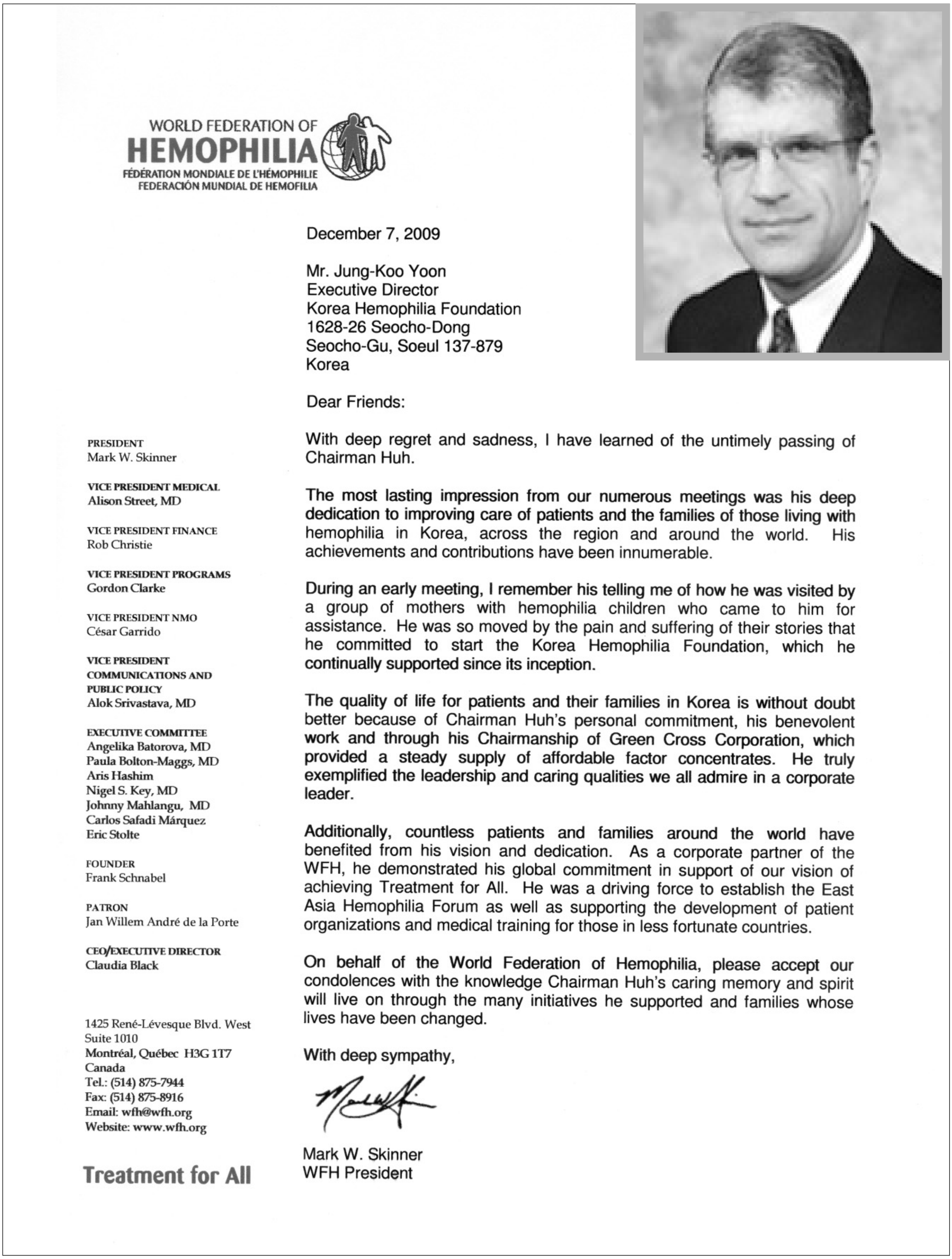
We will keep in mind what you did and how you helped all the patients with a truly sweet heart.

I hope you keep watch us to live right from the heaven. Rest in peace.

We never gave you anything in return and we are sorry that you left alone like this. We would like to say how much we appreciated what you did, but you are not here with us anymore.

His contributions have been innumerable





WORLD FEDERATION OF
HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA

December 7, 2009

Mr. Jung-Koo Yoon
Executive Director
Korea Hemophilia Foundation
1628-26 Seocho-Dong
Seocho-Gu, Soeul 137-879
Korea

Dear Friends:

With deep regret and sadness, I have learned of the untimely passing of Chairman Huh.

The most lasting impression from our numerous meetings was his deep dedication to improving care of patients and the families of those living with hemophilia in Korea, across the region and around the world. His achievements and contributions have been innumerable.

During an early meeting, I remember his telling me of how he was visited by a group of mothers with hemophilia children who came to him for assistance. He was so moved by the pain and suffering of their stories that he committed to start the Korea Hemophilia Foundation, which he continually supported since its inception.

The quality of life for patients and their families in Korea is without doubt better because of Chairman Huh's personal commitment, his benevolent work and through his Chairmanship of Green Cross Corporation, which provided a steady supply of affordable factor concentrates. He truly exemplified the leadership and caring qualities we all admire in a corporate leader.

Additionally, countless patients and families around the world have benefited from his vision and dedication. As a corporate partner of the WFH, he demonstrated his global commitment in support of our vision of achieving Treatment for All. He was a driving force to establish the East Asia Hemophilia Forum as well as supporting the development of patient organizations and medical training for those in less fortunate countries.

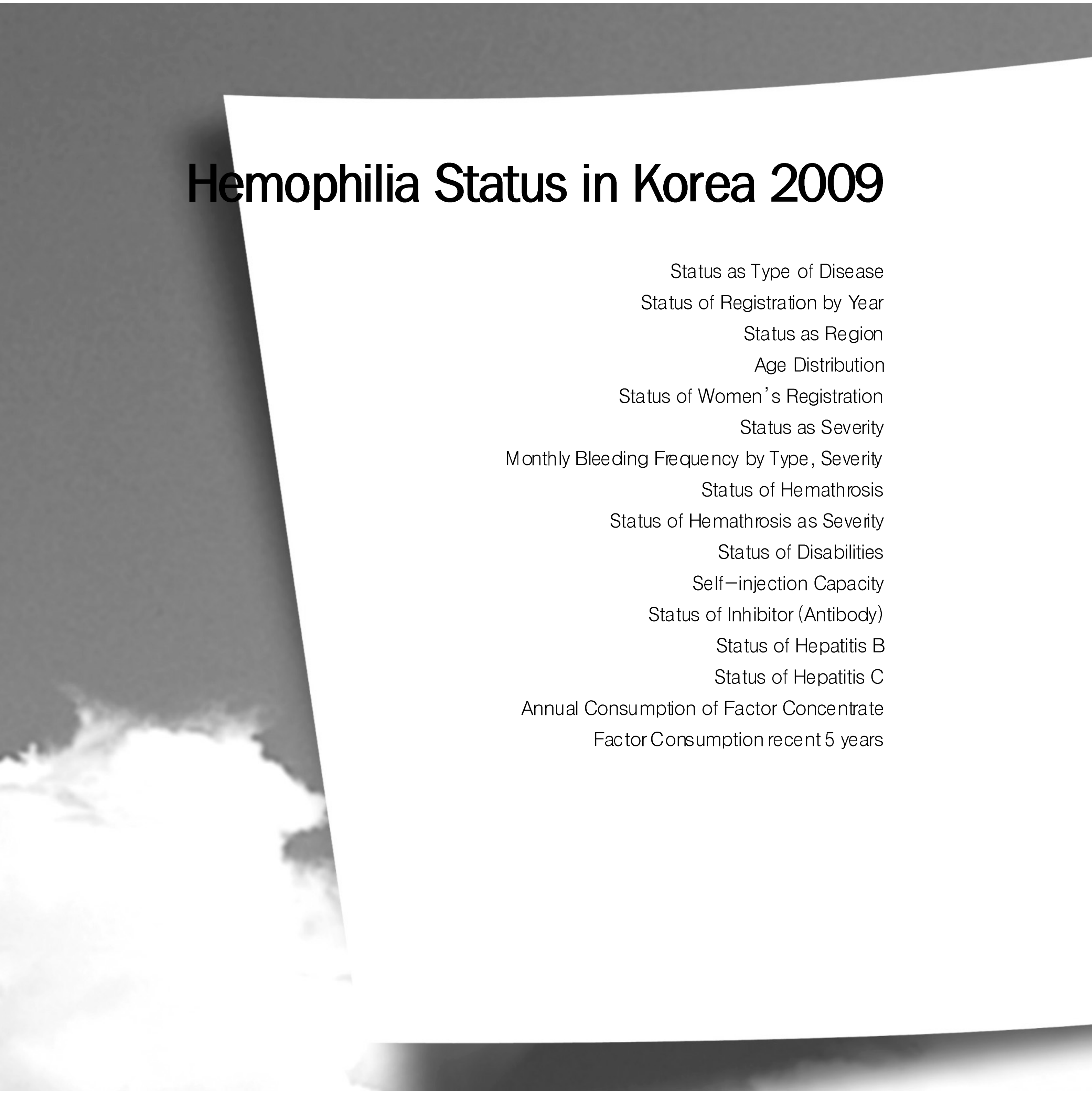
On behalf of the World Federation of Hemophilia, please accept our condolences with the knowledge Chairman Huh's caring memory and spirit will live on through the many initiatives he supported and families whose lives have been changed.

With deep sympathy,

Mark W. Skinner
WFH President

1425 René-Lévesque Blvd. West
Suite 1010
Montréal, Québec H3G 1T7
Canada
Tel.: (514) 875-7944
Fax: (514) 875-8916
Email: wfh@wfh.org
Website: www.wfh.org

Treatment for All



Hemophilia Status in Korea 2009

Status as Type of Disease
Status of Registration by Year
Status as Region
Age Distribution
Status of Women's Registration
Status as Severity
Monthly Bleeding Frequency by Type, Severity
Status of Hemathrosis
Status of Hemathrosis as Severity
Status of Disabilities
Self-injection Capacity
Status of Inhibitor (Antibody)
Status of Hepatitis B
Status of Hepatitis C
Annual Consumption of Factor Concentrate
Factor Consumption recent 5 years

Hemophilia Status in 2009

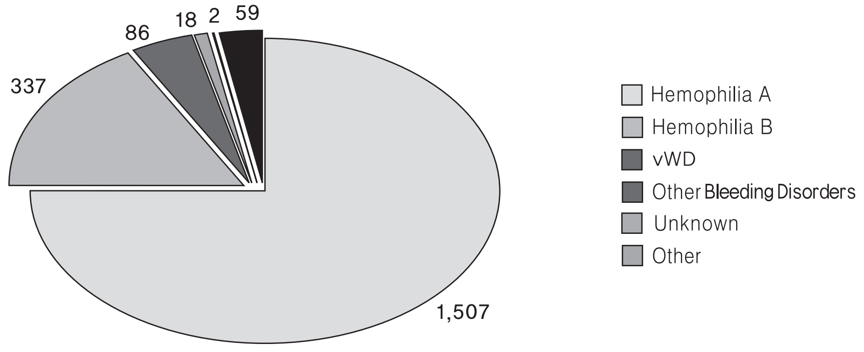
KHF was transferred of work on registration and management of hemophilia patients from Health Society department in March, 1991, right after KHF was established. Each medical facility is supposed to contact KHF once a patient is diagnosed with hemophilia and KHF supports all the registered patients to help hemophilia management and education.

In December 31st, 2009, hemophilia patients and other bleeding disorder patients registered in KHF were total of 2,009 and the majority of them are 1,507(75.0%) of Hemophilia A patients.

Hemophilia patients and other bleeding disorder patients registered in KHF are shown below. (Basic date : December 31st, 2009)

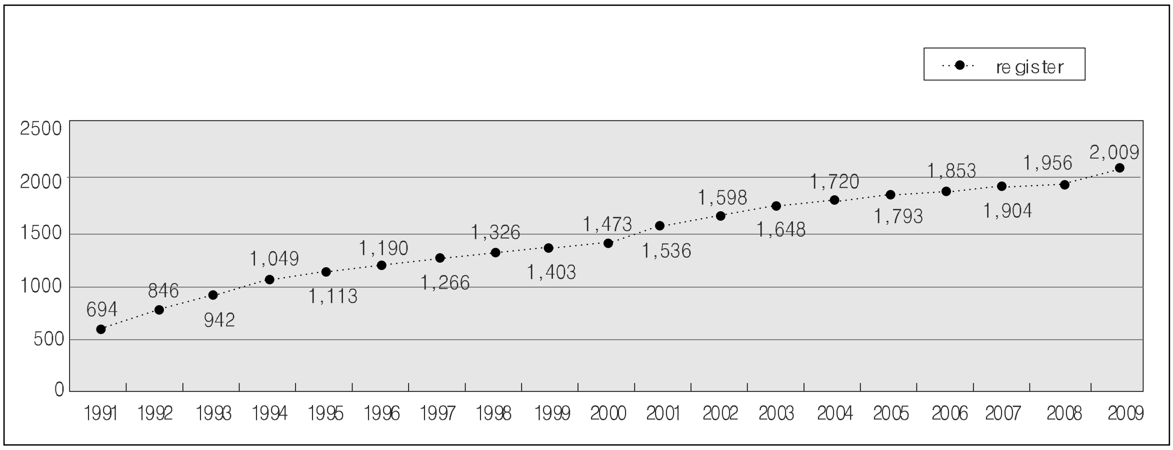
Status as Type of Disease

Type	No. of Patients	Rate	New Patients in 2009	Rate
Hemophilia A	1,507	75.0%	41	65.1%
Hemophila B	337	16.8%	12	19.0%
vWD	86	4.3%	5	7.9%
Factor I Deficiency	4	0.2%	0	0.0%
Factor V Deficiency	2	0.1%	0	0.0%
Factor VII Deficiency	20	1.0%	1	1.6%
Factor XI Deficiency	13	0.6%	1	1.6%
Factor XII Deficiency	3	0.1%	0	0.0%
Factor XIII Deficiency	4	0.2%	0	0.0%
Multi Factor Deficiency	5	0.2%	1	1.6%
Acquired cagulation factor deficiency	8	0.4%	0	0.0%
Other	18	0.9%	1	1.6%
Unknown*	2	0.1%	1	1.6%
Sum	2,009	100.0%	63	100.0%



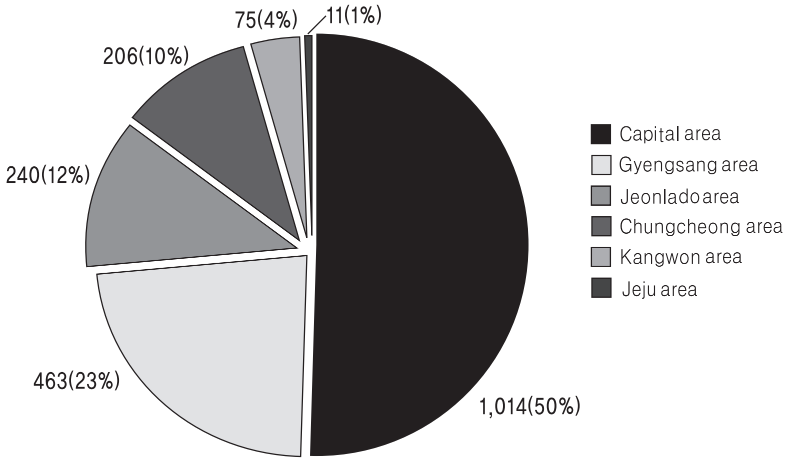
Status of Registration by Year

Year	Hemophilia A	Hemophilia B	vWD	Other	New Patients	Death	Total
1991	588	105	2	1	696	2	694
1992	139	18	0	1	158	6	846
1993	83	12	2	4	101	5	942
1994	95	14	4	0	113	6	1,049
1995	54	9	5	2	70	6	1,113
1996	66	9	4	2	81	4	1,190
1997	63	13	5	2	83	7	1,266
1998	45	12	10	2	69	9	1,326
1999	65	12	1	3	81	4	1,403
2000	55	14	5	4	78	8	1,473
2001	41	11	11	8	71	8	1,536
2002	43	10	11	5	69	7	1,598
2003	32	18	4	5	59	9	1,648
2004	45	18	7	8	78	6	1,720
2005	42	21	4	12	79	6	1,793
2006	43	13	3	5	64	4	1,853
2007	39	12	1	6	58	7	1,904
2008	35	17	2	9	63	11	1,956
2009	41	12	5	5	63	10	2,009
Sum	1,614	350	86	84	2,134	125	



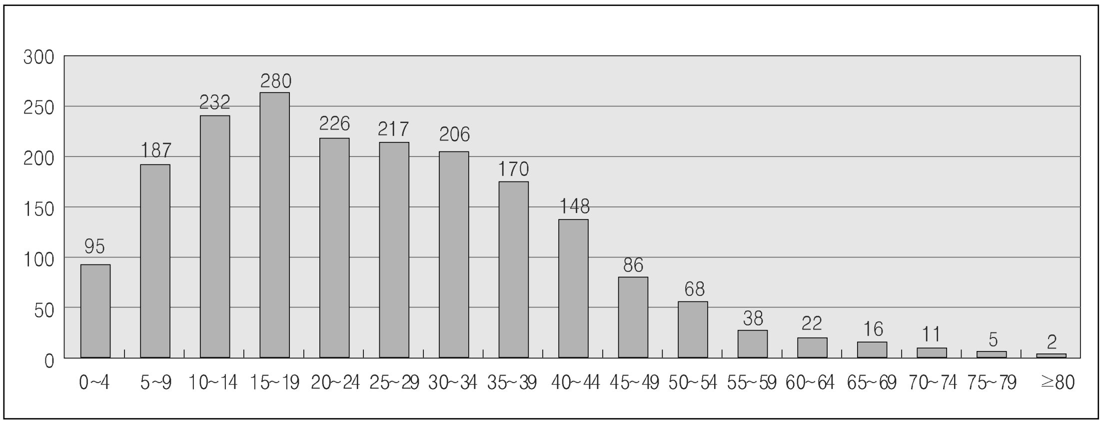
Status as Region

Region	Hemophilia A	Hemophilia B	vWD	Other	Total	Rate
Seoul	345	63	23	24	455	22.6%
Busan	90	21	2	3	116	5.8%
Daegu	83	13	5	2	103	5.1%
Incheon	60	15	7	6	88	4.4%
Gwangju	48	26	4	2	80	4.0%
Daejeon	59	8	0	2	69	3.4%
Ulsan	34	2	0	2	38	1.9%
Kangwon-do	64	8	2	1	75	3.7%
Gyenggi-do	351	84	18	18	471	23.4%
Gyengsangnam-do	89	16	1	4	110	5.5%
Gyengsangbuk-do	61	17	16	2	96	4.8%
Jeonlanam-do	48	27	2	4	81	4.0%
Jeonlabuk-do	65	9	1	4	79	3.9%
Chungcheongnam-do	52	14	5	2	73 3	.6%
Chungcheongbuk-do	49	12	0	3	64	3.2%
Jeju-do	9	2	0	0	11	0.5%
Sum	1,507	337	86	79	2,009	100.0%



Age Distribution

Age(r)	Hemophilia A	Hemophilia B	vWD	Other	Total	Rate
0~4	73	20	0	2	95	4.7%
5~9	125	41	5	16	187	9.3%
10~14	158	42	15	17	232	11.5%
15~19	210	37	17	16	280	13.9%
20~24	162	37	18	9	226	11.2%
25~29	171	33	6	7	217	10.8%
30~34	164	34	7	1	206	10.3%
35~39	135	26	5	4	170	8.5%
40~44	117	26	4	1	148	7.4%
45~49	69	13	3	1	86	4.3%
50~54	55	12	1	0	68	3.4%
55~59	30	7	0	1	38	1.9%
60~64	17	2	2	1	22	1.1%
65~69	11	2	2	1	16	0.8%
70~74	5	4	1	1	11	0.5%
75~79	3	1	0	1	5	0.2%
≥80	2	0	0	0	2	0.1%
Sum	1,507	337	86	79	2,009	100.0%



Status of Women's Registration

Type	No. of patients	Rate
Hemophilia A	5	5.0%
Hemophilia B	1	1.0%
vWD	33	32.7%
Factor I Deficiency	2	2.0%
Factor VII Deficiency	0	0.0%
Factor XI Deficiency	12	11.9%
Factor XII Deficiency	4	4.0%
Factor XIII Deficiency	1	1.0%
Multi factor deficiency	3	3.0%
Acquired factor deficiency	2	2.0%
Other*	36	35.6%
Unknown	1	1.0%
Total	101	100.0%

※Other : Include carriers who has bleeding symptom.

Age(r)	Hemophilia A	Hemophilia B	vWD	Other	Total	Rate
0~4	1	0	0	1	2	2.0%
5~9	1	0	1	9	11	10.9%
10~14	1	0	6	8	15	14.9%
15~19	1	0	4	7	12	11.9%
20~24	0	0	6	6	12	11.9%
25~29	0	0	2	4	6	5.9%
30~34	1	0	3	5	9	8.9%
35~39	0	1	3	6	10	9.9%
40~44	0	0	3	6	9	8.9%
45~49	0	0	2	2	4	4.0%
50~54	0	0	1	3	4	4.0%
55~59	0	0	0	2	2	2.0%
60~64	0	0	0	2	2	2.0%
65~69	0	0	1	0	1	1.0%
70~74	0	0	1	1	2	2.0%
75~79	0	0	0	0	0	0.0%
≥80	0	0	0	0	0	0.0%
Sum	5	1	33	62	101	100.0%

Status as Severity

Type	Severe	Moderate	Mild	Unknown	Total
Hemophilia A	1,007 (66.8%)	322 (21.4%)	159 (10.6%)	19 (1.3%)	1,507 (100.0%)
Hemophilia B	201 (59.6%)	89 (26.4%)	43 (12.8%)	4 (1.2%)	337 (100.0%)
Total	1,208 (65.5%)	411 (22.3%)	202 (11.0%)	23 (1.2%)	1,844 (100%)

※ Severe : <1%, Moderate : 1.1~5%, Mild : >5.1%

Monthly Bleeding Frequency by Type, Severity

Type	Severity	<1	1~2	3~4	5~8	≥9	Unknown	Total
Hemophilia A	Severe	43 (4.3%)	223 (22.1%)	425 (42.2%)	204 (20.3%)	23 (2.3%)	89 (8.8%)	1,007 (100%)
	Moderate	97 (30.1%)	94 (29.2%)	75 (23.3%)	11 (3.4%)	1 (0.3%)	44 (13.7%)	322 (100%)
	Mild	79 (49.7%)	17 (10.7%)	3 (1.9%)	0 (0.0%)	0 (0.0%)	60 (37.7%)	159 (100%)
	Unknown	1 (5.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	18 (94.7%)	19 (100%)
	Total	220 (14.6%)	334 (22.2%)	503 (33.4%)	215 (14.3%)	24 (1.6%)	211 (14.0%)	1,507 (100%)
Hemophilia B	Severe	22 (10.9%)	54 (26.9%)	84 (41.8%)	11 (5.5%)	0 (0.0%)	30 (14.9%)	201 (100%)
	Moderate	40 (44.9%)	13 (14.6%)	8 (9.0%)	1 (1.1%)	1 (1.1%)	26 (29.2%)	89 (100%)
	Mild	20 (46.5%)	2 (4.7%)	2 (4.7%)	0 (0.0%)	0 (0.0%)	19 (44.2%)	43 (100%)
	Unknown	2 (50.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (50.0%)	4 (100%)
	Total	84 (24.9%)	69 (20.5%)	94 (27.9%)	12 (3.6%)	1 (0.3%)	77 (22.8%)	337 (100%)

Status of Hemarthrosis

Type	Hemathrosis	None	Total
Hemophilia A	401(26.6%)	1,106(73.4%)	1,507(100.0%)
Hemophilia B	47(13.9%)	290(86.1%)	337(100.0%)
vWD	2(2.3%)	84(97.7%)	86(100.0%)
Other	3(3.8%)	76(96.2%)	79(100.0%)
Total	453(22.5%)	1,556(77.5%)	2,009(100.0%)

Status of Hemarthrosis as Severity

Type	Severity	Hemarthrosis(%)	Unkown(%)	Total(%)
Hemophilia A	Severe	325(32.3%)	682(67.7%)	1,007(100.0%)
	Moderate	72(22.4%)	250(77.6%)	322(100.0%)
	Mild	4(2.5%)	155(97.5%)	159(100.0%)
	Unknown	0(0.0%)	19(100.0%)	19(100.0%)
	Total	401(26.6%)	1,106(73.4%)	1,507(100.0%)
Hemophilia B	Severe	38(18.9%)	163(81.1%)	201(100.0%)
	Moderate	8(9.0%)	81(91.0%)	89(100.0%)
	Mild	1(2.3%)	42(97.7%)	43(100.0%)
	Unknown	0(0.0%)	4(100.0%)	4(100.0%)
	Total	47(13.9%)	290(86.1%)	337(100.0%)
Total		448(24.3%)	1,396(75.7%)	1,844(100.0%)

Status of Family History

Type	Family History	None	Total
Hemophilia A	718(47.6%)	789(52.4%)	1,507(100.0%)
Hemophilia B	139(41.2%)	198(58.8%)	337(100.0%)
vWD	30(34.9%)	56(65.1%)	86(100.0%)
Other	10(12.7%)	69(87.3%)	79(100.0%)
Total	897(44.6%)	1,112(55.4%)	2,009(100.0%)

Self-injection Capacity

Age(r)	Possible	Impossible	Total
0~4	24(25.3%)	71(74.7%)	95(100.0%)
5~9	37(19.8%)	150(80.2%)	187(100.0%)
10~14	58(25.0%)	174(75.0%)	232(100.0%)
15~19	65(23.2%)	215(76.8%)	280(100.0%)
20~24	52(23.0%)	174(77.0%)	226(100.0%)
25~29	49(22.6%)	168(77.4%)	217(100.0%)
30~34	25(12.1%)	181(87.9%)	206(100.0%)
35~39	7(4.1%)	163(95.9%)	170(100.0%)
40~44	9(6.1%)	139(93.9%)	148(100.0%)
45~49	8(9.3%)	78(90.7%)	86(100.0%)
50~54	5(7.4%)	63(92.6%)	68(100.0%)
55~59	1(2.6%)	37(97.4%)	38(100.0%)
60~64	2(9.1%)	20(90.9%)	22(100.0%)
65~69	0(0.0%)	16(100.0%)	16(100.0%)
70~74	0(0.0%)	11(100.0%)	11(100.0%)
75~79	1(20.0%)	4(80.0%)	5(100.0%)
≥80	0(0.0%)	2(100.0%)	2(100.0%)
Total	343(17.1%)	1,666(82.9%)	2,009(100.0%)

Status of Inhibitor(Antibody)

Type	High responder	Low responder	transient	None	Unknown	Total
Hemophilia A	25 (1.7%)	20 (1.3%)	70 (4.6%)	1,320 (87.6%)	72 (4.8%)	1,507 (100%)
Hemophilia B	6 (1.8%)	2 (0.6%)	2 (0.6%)	290 (86.1%)	37 (11.0%)	337 (100%)
Total	31 (1.7%)	22 (1.2%)	72 (3.9%)	1,610 (87.3%)	109 (5.9%)	1,844 (100%)

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

Status of Inhibitor as Severity (Hemophilia A)

Type	Severity				Total(%)
	Severe(%)	Moderate(%)	Mild(%)	Unknown(%)	
High responder (≥ 5BU/㎖)	25 (2.5%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	25 (1.7%)
Low responder	19 (1.9%)	1 (0.3%)	0 (0.0%)	0 (0.0%)	20 (1.3%)
Transient	52 (5.2%)	17 (5.3%)	0 (0.0%)	1 (5.3%)	70 (4.6%)
None	893 (88.7%)	281 (87.3%)	139 (87.4%)	7 (36.8%)	1,320 (87.6%)
Unknown	18 (1.8%)	23 (7.1%)	20 (12.6%)	11 (57.9%)	72 (4.8%)
Total	1,007 (100.0%)	322 (100.0%)	159 (100.0%)	19 (100.0%)	1,507 (100.0%)

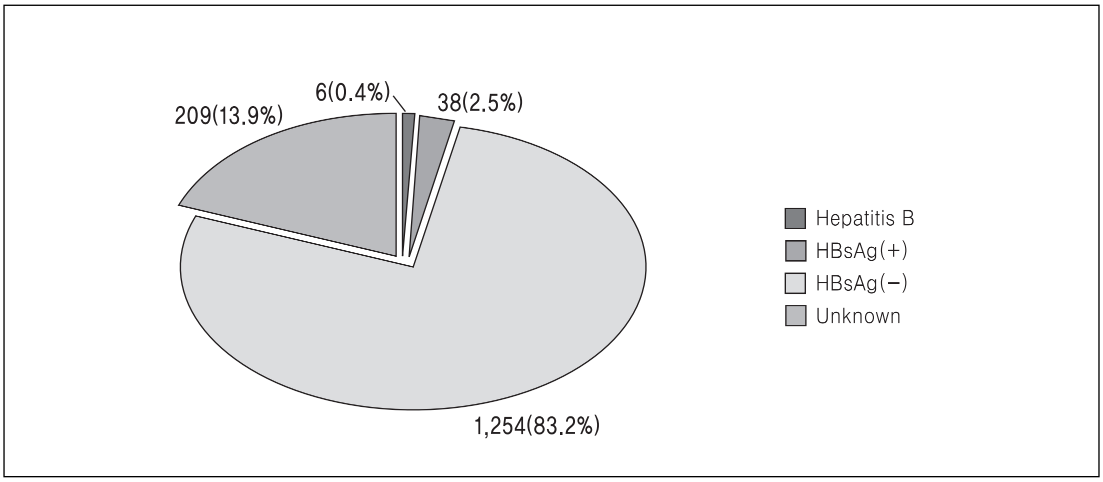
Status of Inhibitor as Severity (Hemophilia B)

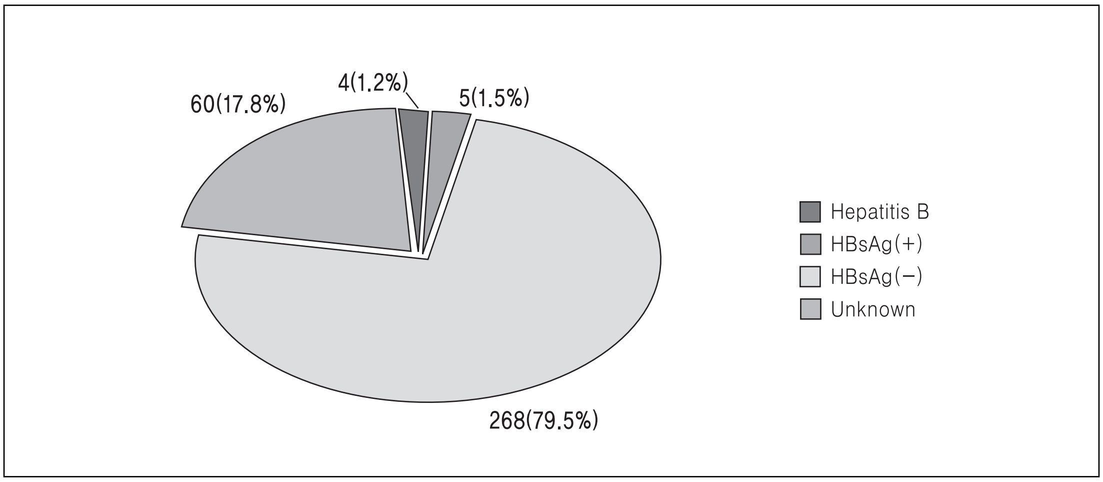
Type	Severity				Total(%)
	Severe(%)	Moderate(%)	Mild(%)	Unknown(%)	
High responder (≥ 5BU/㎖)	6 (3.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	6 (1.8%)
Low responder	2 (1.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (0.6%)
Transient	1 (0.5%)	1 (1.1%)	0 (0.0%)	0 (0.0%)	2 (0.6%)
None	183 (91.0%)	73 (82.0%)	32 (74.4%)	2 (50.0%)	290 (86.1%)
Unknown	9 (4.5%)	15 (16.9%)	11 (25.6%)	2 (50.0%)	37 (11.0%)
Total	201 (100.0%)	89 (100.0%)	43 (100.0%)	4 (100.0%)	337 (100.0%)

Status of Hepatitis B

Type	Hepatitis B	HBsAg(+) (%)	HBsAg(-) (%)	Unknown	Total
Hemophilia A	6(0.4%)	38(2.5%)	1,254(83.2%)	209(13.9%)	1,507(100.0%)
Hemophilia B	4(1.2%)	5(1.5%)	268(79.5%)	60(17.8%)	337(100.0%)
Total	10(0.5%)	43(2.3%)	1,522(82.5%)	269(14.6%)	1,844(100.0%)

※Hepatitis B : HBsAg (+), ALT ≥50
※HBsAg(+) : HBsAg (+), ALT 〈50



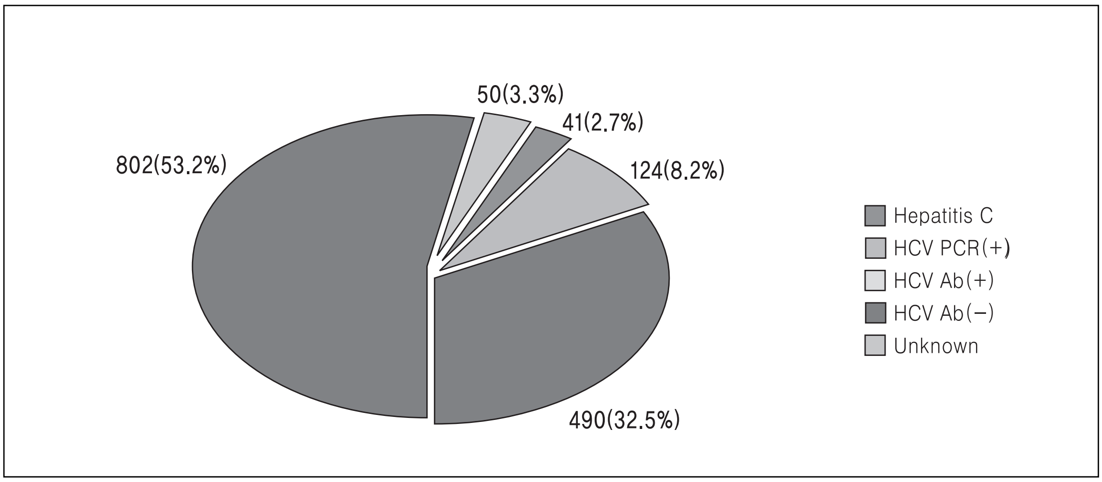


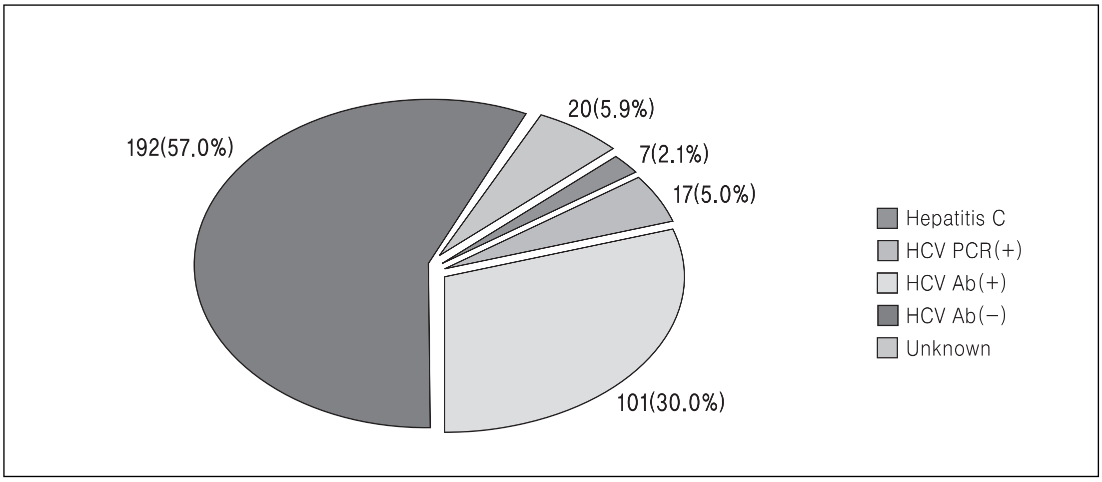
Status of Hepatitis C

Type	Hepatitis C	HCV PCR(+) (%)	HCV Ab(+) (%)	HCV Ab(-) (%)	Unknown	Total
Hemophilia A	41 (2.7%)	124(8.2%)	490(32.5%)	802(53.2%)	50 (3.3%)	1,507 (100.0%)
Hemophilia B	7(2.1%)	17 (5.0%)	101 (30.0%)	192(57.0%)	20 (5.9%)	337(100.0%)
Total	48 (2.6%)	141(7.6%)	591 (32.0%)	994(53.9%)	70 (3.8%)	1,844 (100.0%)

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

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





Annual Consumption of Factor Concentrate at KHF Clinics

(Unit : IU)

Factor	KHF Clinic(Seoul)	KHF Gwangju Clinic	KHF Busan Clinic	Total
PD FVIII	36,903,500	8,104,500	5,176,000	50,184,000
PD FIX	385,750	1,017,000	0	1,402,750
rFVIII	32,110,000	2,217,500	7,691,000	42,018,500
rFIX	13,725,500	2,151,000	2,949,500	18,826,000
aPCC	6,147,500	0	139,000	6,286,500
rF VIIa	65,700	0	10,020	75,720

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

Factor Consumption in Korea in 2009

(Unit : IU)

Factor	in KHF clinics	in Korea	per 1 capita
PD FVIII	50,184,000	74,833,000	1.50
PD FIX	1,402,750	2,270,000	0.05
rFVIII	42,018,500	59,993,500	1.20
rFIX	18,826,000	20,426,000	0.41
aPCC	6,286,500	9,414,000	
rF VIIa	75,720	575,400	

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

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

※Korean population is estimated 50 million according to standard in 2009.

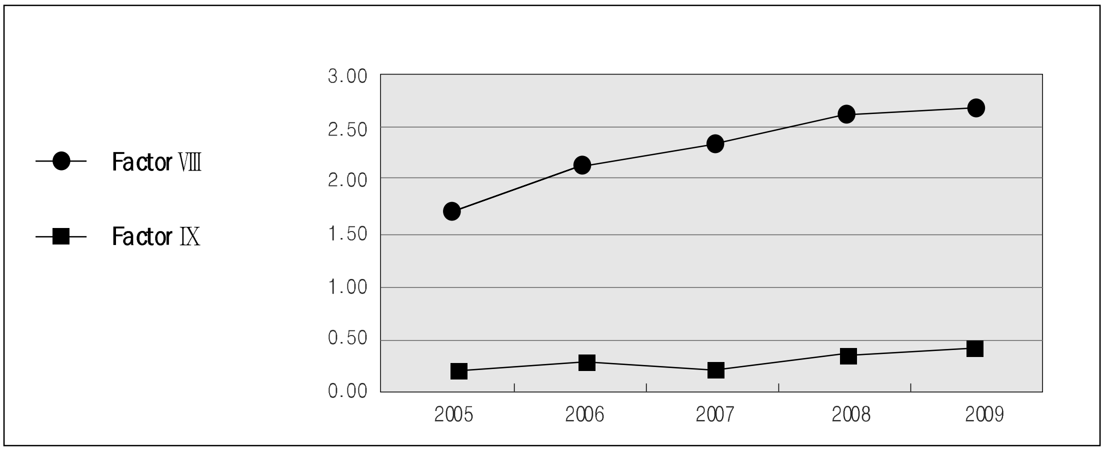
Factor Consumption per 1 patient in 2009

(Unit : IU)

Type	2009			2008	Rate
	No. of patients	Total Consumption	per 1 patient	per 1 patient	
Hemo A	1,507	134,826,500	89,466.82	84,099.66	106.4%
Hemo B	337	22,696,000	67,347.18	58,634.97	114.9%

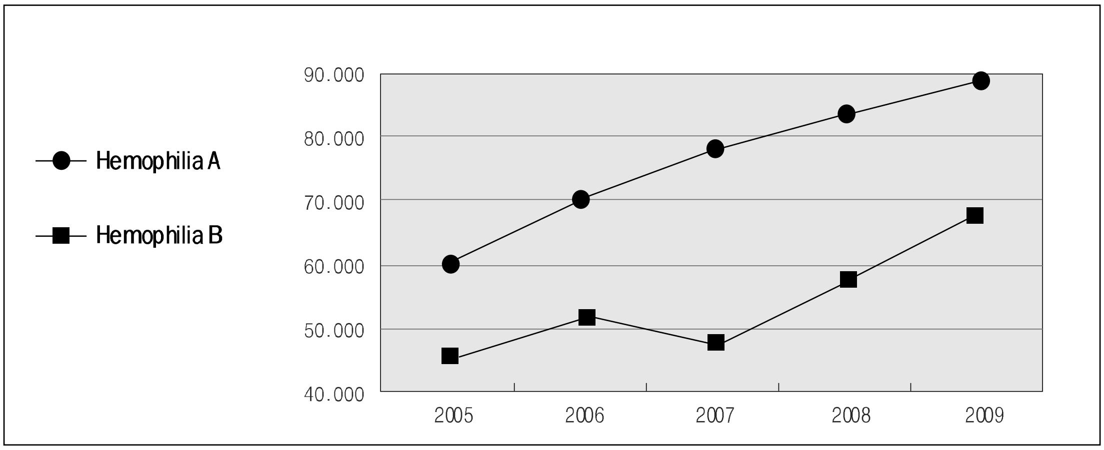
Factor Consumption per 1 capita recent 5 years

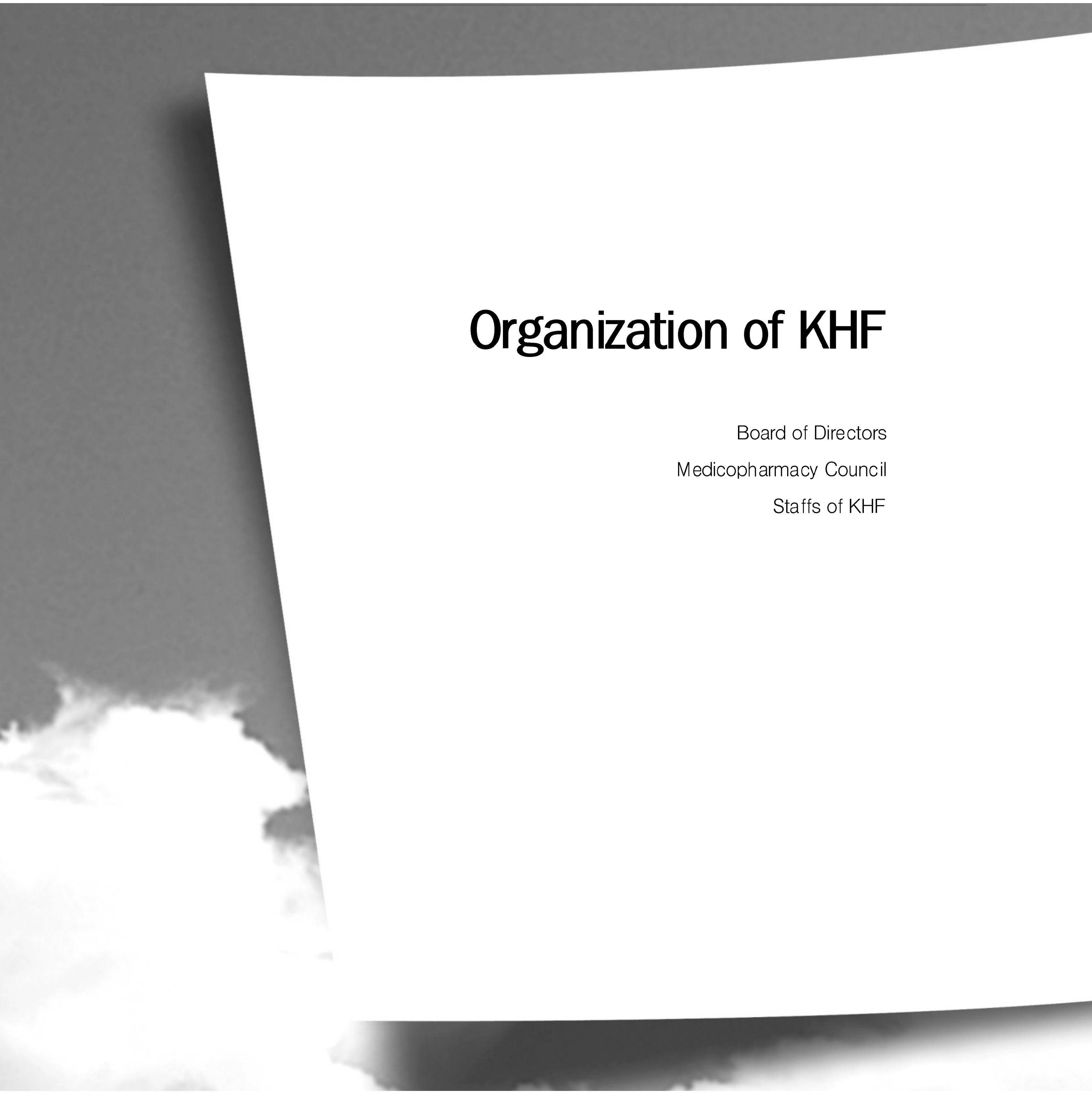
Type	2005	2006	2007	2008	2009
Factor VIII	1.72	2.10	2.39	2.59	2.70
Factor IX	0.27	0.33	0.31	0.40	0.46



Factor Consumption per 1 patient recent 5 years

Type	2005	2006	2007	2008	2009
Hemophilia A	59,688.27	70,743.32	78,728.38	84,099.66	89,466.82
Hemophilia B	45,718.64	52,422.76	48,181.23	58,634.97	67,347.18





Organization of KHF

Board of Directors
Medicopharmacy Council
Staffs of KHF

Organization of KHF

Board of Directors

The Board of Directors consists of 9 directors and 2 auditors, and has regular and special sessions of the meeting to approve business plans and outcomes of the KHF.

The Board of Directors consists of the following members:

△ President: Yong-Mook Choi (Professor at the Pediatrics Department of Kyung Hee University)

△ Advisors: Soon-Yong Lee (Professor at the Pediatrics Department of the Inje University Baek Hospital)
Myung-Chul Yoo(Professor at the Orthopedics Department of Kyung Hee University) - served as an advisor and director

△ Directors: Jung-Koo Yoon (Executive Director of the KHF)
Tai-Ju Hwang (Professor at the Pediatrics Department of the Chonnam National University Hospital)
Kun-Soo Lee (Professor at the Pediatrics Department of the Kyungpook National University Hospital)
Seon-Yang Park (Professor at the Hematology/Oncology Department of Seoul National University)
Young-Min Choi (Professor at the Obstetrics and Gynecology Department of Seoul National University)
Sang-Gyu Park (Professor at the Pediatrics Department of the University of Ulsan)
Young-Jin Jang (Hemophiliac, teacher at Seogang High School)

△ 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 : Tai-Ju Hwang (Professor of Chunnam National University)
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)
Jung-Koo Youn (Executive Director of KHF)
Ki-Young Yoo (Director of KHF clinic)

Staffs of KHF

A total of 29 staffs 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 December 2009, the KHF has the following staff members:

△ Executive Director: Jung-Koo Yoon
△ Executive office (FTEs: 9)
- Director of Executive Office: Kang-Ik Lee
- Administration: Seol-Woon Hwang (Vice-director)
  Myung-Hee Lee (Manager)
  Tae-Hyung Gu (Manager)
  Sang-Ho Kim
- Welfare & Planning: Dae-Guen Lee (Manager)
  Hye-Sook Noh (Manager)
  Yun-Jung Kim (Social Worker)
  Jong-Wan Woo

△ KHF Clinic (FTEs: 11)
- 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
- Clinical Laboratory: Soo-Young Jung (Assistant Manager)
  Mi-Ran Lee
  Jin-Young Choi
- Radiology: Jin-Guk Kim
- Administrating Assistant: Mi-Yeon Yoo

△ KHF Gwangju Clinic (FTEs: 4)
- Director: Young-Soo Chun, M.D.
- Nurse: Soo-Yeon Lee
- Physical Therapist: Eun-Jung Yoon
- 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 Welfare Service Team (Local Staff: 4)
- Daegu/Gyengsangbuk-do: Young-Ja Kim (Counselor)
- Busan/Gyengsangnam-do: Sun-Kyung Kim (Counselor)
- Gwangju/Jeonlanam-do: Eun-Hee Song (Counselor)
- Jeonlabuk-do: Sang-Jin Park (Counselor)