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Perspective

Korea Blood Cancer Association: for supporting the patients suffering from blood cancers

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A brief history

On the 21st anniversary in this year, I recall the small beginning of the Korea Blood Cancer Association (KBCA). Back in 1993, I myself was diagnosed with acute myeloid leukemia and undergone seven cycles of chemotherapy after a failure of remission therapy. Besides I had to get lung surgery due to the side effect associated with the chemotherapy. Passing through this 'death tunnel', however, I was recovered completely. After overcoming my painful experience, I began to feel that an organization which can help the patients suffering from blood cancers similar to mine is truly needed.

In December 1995, together with the congenial colleagues who also experienced leukemia as patients, I launched a small organization named 'Saebitnurihoe', which means 'a new light to the world', to fulfil the mission of helping the patients with blood cancers. It was the first supporting group for adult blood cancer patients in Korea. Although

many of my co-workers had passed away due to the recurrence of the painful disease, I have fortunately survived to continue doing our duty. We have been trying to support the patients and their families emotionally and financially to go through difficult times fighting the disease.

In February 2003, we could make a big progress to establish the KBCA which was authorized by Ministry of Health and Welfare in Korea as a non-profit organization. Since then, we have been providing a wide variety of supporting activities. Our members are composed mainly of office workers who have experienced blood cancer, nurse specialists, and social workers. This patient-friendly cooperation system makes us to get more attentive to patient's needs and offer the best services for the patients. And most thankfully, we have many other dedicated helping hands from volunteers, sponsors, and medical doctors. Having in our hearts two mottos, 'giving Hope' and 'sharing Information', we work together in one accord to fulfill our mission. We are trying to provide the eight key services for the patients: counseling, financial support, emotional support, improving the quality of life, education programs for medical knowledge, programs for returning to normal life, publications, and international partnership.

Counseling

We are trying our best to deal with patients' emotional and financial problems from the patients' and their families' point of view. In our efforts to support patients and their families by discussing the problems that they might face in the early phase of the disease including psychological distress, sense of loss, and lack of information as well as the emotional, financial, and family-related problems that they often encounter, we offer the telephone and face-to-face counseling services. And also we open the online counseling, which provide professional advices by the medical experts, and frequently asked questions and symptoms can

be searched in the counseling internet homepage.

Financial support

Once the father or mother becomes ill, the ordinary family collapses. Our organization provides financial supports to adult and pediatric leukemia patients to share their burden of physical pain and high cost of medical fees. We support the cost of treatment (drug coverage) and provide blood donor cards which can later be used for transfusion at no cost. The recent progress of our budget from 2009 to 2015 is shown in Fig. 1. According to increase in the budget, number of beneficiaries has also been increased (Fig. 2). The major financial supports have been sponsored by Hyundai Home Shopping and Korea Agro-Fisheries & Food Trade Corporation. We are thankful to the companies for their contributions that could help many more patients start new lives.

Emotional support

In order to refresh patients from their emotional distress over cancer and to raise hope of cure, we offer a variety of special services. For patients and their families who were in difficult situation due to long term treatment, we provide them 2 days and 1 night stay at a beautiful resort condo to encourage them to make wonderful memories in beautiful atmosphere and gain positive strengths for their lives. Other programs include mountain climbing and picnic for recreational events, where the patients also have an opportunity to get medical counseling.

Improving the quality of life

We offer hygiene management service for the immunocompromised patients who had just completed chemotherapy or stem cell transplantation. A professional company that makes safe and sterile environment sponsors this infection control program to prevent infection at home.

Fig. 1. Recent progress of the KBCA budget from 2009 to 2015.

Furthermore, we are running 'wig clinic' for adult women cancer patients who commonly experience stress from changing in appearance due to hair loss after chemotherapy. We are working with a wig company specialized in making wigs for cancer patients to improve their quality of lives.

Education programs for medical knowledge

We believe that 'knowledge is power'. Many patients want to learn about their disease. We have various education programs and workshops for the patients and caregivers to help better understand the blood cancers regarding the diagnosis, treatment, and prognosis. We have an open lecture program supported by the Korean Society of Hematology (Fig. 3). It is a large scale project which provides an opportunity to hear from the medical professionals. We also have a small group seminar entitled 'Hope solution' for patients with same disease in a friendly atmosphere

Fig. 2. Increase in the number of cumulated beneficiaries according to their diseases.

Fig. 3. Open lecture program for patients and their families to provide recent medical information supported by the Korean Society of Hematology.

at the education center. And 'Online & Hotline Seminar' is also available for people who are not able to attend offline lecture. So far, our education programs are held more than 50 lectures and about 3,000 patients are attending every year.

Programs for returning to normal life

The 'Hope & Information Education Center' affiliated with the KBCA opens 300-350 lectures under the title of 'returning to normal life'. A 'Mentoring Program' provided by a support group of patients and their families gives a chance to meet others who have been in the similar situation for sharing information, asking questions, and giving hope each other. In addition, customized education programs including 'Music therapy', 'Cinema therapy', and 'Cooking Guide for cancer patients' are ongoing to support their daily normal lives.

Publications

Monthly magazine entitled 'Hope' has been published for 21 years and now it becomes one of the most important symbolic activities that represent the KBCA. The 'Hope' contains a wide variety of information including stories of patients and caregivers telling about how they overcome the blood cancers, doctors' advices and recent medical information, nutrition class for sharing the recipes for the patients, body-mind practices, and other informative interesting contents. The magazine has been distributed

monthly free of charge to over 8,000 readers including patients, hospitals, and our supporters. We also publish 'Guide book by diseases' and 'Stories of hope' to share information about the disease and to help ease the burden on patients impacted by blood cancers.

International partnership

We are having international partnerships with 'Tsubasa' in Japan and International Myeloma Foundation (IMF) in USA. International exchange programs are held 4 to 5 times every year and we learn about new programs that can be applied to our patients.

Perspectives

Many blood cancer patients still have lives of long-suffering. They have to persevere with many difficulties including the physical and emotional pain and the financial problems. We hope that the government should develop enhanced policies and strategies that enable the patients to be treated at affordable costs. The KBCA will continue to offer practical supports to blood cancer patients. We would like to promote collaborations with other organizations through exchange programs and also with the Korean Society of Hematology to provide the best services to help the patients overcome their difficulties and improve quality of life up until they are cured.

FILLER PHOTO

FRUITFUL OUTCOME AFTER CHERRY BLOSSOM, KOREA S.W. KWON