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Perspective

Hope for better environments in overcoming and curing blood cancer

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It was 17 years ago when my life was shattered by the disease acute myeloid leukemia. I had to undergo extremely painful treatment procedures to fight-off the disease. The first chemotherapy session was a failure, and so I had to go through 7 more chemotherapy sessions and even a lung surgery for the treatment of complications of anticancer treatments. After enduring 4 years of aggressive treatment to cure AML, I decided to form an organization to support and care for patients suffering from this awful disease. Thus, having survived the long fight against AML, I became a co-founder of the Korea Blood Cancer Association (KBA).

The KBA is a unique organization that provides support to adult blood cancer patients. It was first established as the Saebitnuri Association in December, 1995, by patient volunteers who overcame their diseases, with the view to help, support, and share the pains of other blood cancer patients and their families. The Saebitnuri association was reborn as the KBA in February, 2003, and was officially authorized as an incorporated body under the Department of Cancer Policy, the Ministry of Health and Welfare. The motto of the KBA is "hope and information," and the association has been active in various programs directed at helping patients.

The ultimate mission of KBA is to help patients overcome their diseases in better environments and provide support so that they recover completely. Because I, myself, have

suffered from blood cancer and 80% of the full-time staff at the KBA has first-hand experience of the struggle against blood cancer, we do not regard our work as "just a job;" in fact, we provide the best support for blood cancer patients by embracing them on their stance. On the basis of their own experience of receiving medical treatment, our employees alleviate the anxiety of patients undergoing treatment; in addition, they also provide them with practical help by educating them regarding various issues such as treatment, lifestyle, and nutrition. Since we have blood disease experts in the Board of Directors, we can chart out several programs that enable the patients to interact with the medical team, which in turn, helps improve the quality of medical consultation and related services.

The patient-oriented services provided by the KBA can be classified into the following 6 categories: medical treatment support (medical and drug expenses and blood donation card), consultation (information center "HOPE," Q&A forum at our website, and counseling by phone or visit), education (medical seminar on blood diseases), self-support (mountain climbing, picnic, etc), publication (monthly newsletter "HOPE" and disease guidebook distributed for free), and collaborations with other organizations (local and overseas exchange program).

The KBA is primarily involved in sharing the patients' difficulties by providing them financial support for treatment and blood donation cards. A major percentage of support is sourced by many commercial organizations, including Hyundai Home Shopping, Korea Agro-Fisheries Trade Corp., and Money Today; other organized ventures; and individuals.

With the view to providing patients with practical guidelines, the information center, "HOPE," facilitates personal interaction between patients and "the survivors (KBA staff)" and has launched a Q&A forum at our website. Education programs, such as seminars on blood diseases, are open to any individual seeking support and accurate medical in-

formation during his/her fight against cancer. To improve patients' understanding about their disease and treatment, we publish guidelines for overcoming blood diseases and the monthly newsletter "HOPE," which contains survivor's essays and information regarding medicine, social welfare system, and nutrition. More than 7,000 copies of "HOPE" are distributed every month for free. The KBA also organizes cultural events that help patients interact closely and provide physical and mental support. The association is also involved in on-going overseas' exchange programs under collabo-

ration with organizations in the USA and Japan.

Korean Society of Hematology (KSH) will continue to develop advanced treatment modalities. And we hope that the KSH will try on improving the reimbursement system of the health insurance to help patients suffering from physical as well as mental pain due to financial burden. Lastly, we hope see the day when the KBA and the KSH will work together to provide the patients with better environments for overcoming blood cancer and achieving complete cure.

