

International Affiliates
UPDATES FROM AROUND THE GLOBE
Report from IMF Japan

By Daisuke Nakao

IMF Japan was founded by myeloma patient Akira Horinouchi in 1997, after he relapsed from an autologous transplant. Aki found comfort and drew strength from the IMF and its listserv (mailing list). He wanted to share with other myeloma patients in Japan the benefits that he received through his relationship with the IMF. Aki became the driving force behind IMF Japan with his commitment to reach out to people across Japan to offer support and let them know that they are not alone in their battle with this disease. Aki also inspired members to support the search for a cure by raising funds to benefit myeloma research.

Today, IMF Japan not only keeps Aki's vision and spirit alive, it continues to grow and serve more people in more ways. IMF Japan is currently being run by seven board members, headed by Midori Horinouchi, Akira's wife. The mission of IMF Japan is based on four pillars:

1. Provide accurate and timely information in Japanese
2. Connect patients and their medical teams
3. Provide for a patient community
4. Work towards a cure

IMF Japan publishes a bi-annual community magazine, "Ganbarimassyoi," which is colloquial Japanese for "Give it a try." We also host seminars and study sessions all over Japan, the latter being held in co-operation with the Japan Myeloma Study Group (JMSG)[TW1]. We maintain an information website, which also hosts a community bulletin board (<http://myeloma.gr.jp>). IMF Japan also provides funding for promising myeloma research and clinical trials through [TW2]its annual Aki Award research grant. We also petition the national government and Diet representatives for the rapid approval of new drugs.

Every November, IMF Japan holds its annual Patient & Family Seminar, at a different location each year to make it more accessible to members around the country. These seminars are full-day events, with a lot of talking and a lot of studying. The faculty presenters are some of the best myeloma specialists in Japan, all belonging to the JMSG, which is headed by Dr. Shimizu, who is also on the scientific advisory board of the IMF. IMF Japan seminars are scheduled on the day following the annual meeting of the JMSG so as to make scheduling easier on the doctors.

The 12th annual seminar was held on November 21-22, 2009. Niigata City, a large port-city facing the Sea of Japan, provided a fascinating setting for the meeting. Niigata is famous for its rice and

sake (rice wine).

The 12th annual seminar was very special in a number of ways[TW3]. We had a record turnout of more than 200 participants. For the first time, JMSG and IMF Japan totally integrated their respective annual events into a two-day event. The first day targeted the medical professional community (though patients were free to attend), and the second day was dedicated to patients and their families (although doctors were free to attend as well).

The first day of the event was a departure from previous JMSG annual meetings in that the role of “co-medicals” (such as nurses and pharmacists) were highlighted as key players of the medical team. Talks were given on themes such as nursing, medication control, and patient-doctor relationships, with each presentation followed by a panel discussion. I was pleased to present the patient-doctor relationship talk on behalf of IMF Japan.

The 2009 IMF Japan meeting was a momentous event for the myeloma community in Japan, but there was something even more special that weekend. IMF president Susie Novis and chairman of the board Dr. Brian Durie flew in to join us at the meeting! There was a dinner with the IMF staff on Friday, presentations on Saturday, followed by a Saturday dinner party with patients, family members, and staff, and on Sunday, a family member talk session headed by Susie. A lot of patients and family members who heard Susie and Brian talk came up to us and said that they have not been so comforted, felt so cared for in a long while. Brian and Susie, they do have a magic touch!

Brian and Susie, many many thanks from all of us at IMF Japan. Together, we will continue to significantly further the cause of myeloma education and awareness in Japan. We hope to see you visiting us again soon! **MT**



Susie Novis and Dr. Brian Durie being introduced to the seminar participants



IMF Japan's Kyoko Joko and Daisuke Nakao with Susie Novis and Dr. Brian Durie at the closing ceremonies. In the background is IMF Japan's "Thank You Doctor Tree" with letters from myeloma patients.