

## **A Message from the President**

### **Dear Reader,**

As 2009 draws to a close, the first question is “WHERE DID IT GO?!” This has been an incredibly busy year, and I'm pleased to report that the IMF has been very productive on all fronts. So, I would like to take this opportunity to share with you what we've accomplished in our four main areas of focus.

### **Research:**

As the myeloma community entered the era of tailored treatments, with new approaches aimed at customizing each patient's treatment to his or her specific needs, the successes of the IMF's International Myeloma Working Group (IMWG) will soon make it possible for myeloma to be managed as a chronic disease. The IMWG consists of 110 investigators from around the world who have joined together to advance the science and other clinical aspects of myeloma. To date, IMWG members have had 26 papers published in the most prestigious peer-reviewed medical journals with more papers currently pending. In June 2010 they will meet for a “Summit” where they will focus on 5 key areas: epidemiology, diagnostic testing, molecular approaches for assessment of biology, diagnosis and treatment, new drugs, and updating the Myeloma Management Guidelines. The IMF's innovative research program has a strategic plan to make myeloma truly a chronic disease and bring us to the cure.

### **Education:**

Since the founding of the IMF 19 years ago, the way people get information has changed dramatically. From having very few outlets in the past, today's patients have a myriad ways to obtain the information they seek. Millions use the Internet as their “go to” resource, some prefer publications in hard copy, others want to talk to an actual person and utilize the IMF Hotline, and others prefer to attend a seminar. However, we're finding that a majority uses a mix of all of the above -- and that's great. This year the IMF held numerous Patient & Family Seminars and Regional Community Workshops across the U.S. and around the world. Patients and their families learned about the advances in myeloma treatment and management from world experts and also learned from each other. The exchange of information and personal experiences is such an empowering and positive experience -- one that just can't be beat. This year, we continued to enrich the content available through our website. Over 1 million visits to the website and over 6 million page views is something we're proud of, continuing to provide information for patients, family members, doctors, nurses, healthcare providers, and other interested parties. We reported on ground breaking news, conducted interviews, wrote articles, disseminated published papers from the International Myeloma Working Group and from the Nurse Leadership Board, produced videos -- lots of videos -- from interviews with Key Opinion Leaders on key topics (and in multiple languages, too!), to educational videos for patients,

clinicians and nurses. And our library now has over 100 publications in various languages on a wide variety of topics far too many to name. It's no wonder that the IMF is the number one resource for information about myeloma in the world!

**Support:**

The IMF works with over 100 Support Groups and I'm so proud of the work that they do to reach out in their communities to help others with myeloma. The IMF's 3 Support Group Coordinators criss-crossed the country visiting Support Groups to ensure that they had what they needed -- everything from a place to hold their meetings, supplying them with materials, as well as securing outstanding speakers to keep them abreast of advances in myeloma treatment and research. And we held the 10th Annual Support Group Leaders Retreat, which brought together Leaders from groups across the country.

**Advocacy:**

In 2009 the IMF launched a new initiative to support and advance myeloma legislation and priority policies. The Cancer Patient Statement of Principles lies at the center of this effort, focusing on prevention, innovation, equality of access and insurance coverage, early approval of new treatments and access to experimental treatments for patients who have exhausted all other possibilities. This initiative will educate and inform potential myeloma advocates about the legislative process and public policy to ensure positive changes for myeloma patients and their families. We also established an on-line Advocacy Action Center, a "one-stop-shop" for federal legislative and regulatory information that helps IMF members quickly and effectively communicate with their Congressional Members on issues the IMF is tracking. To join the Myeloma Action Network, receive advocacy updates, and see the IMF's public policy statements, please visit [www.myeloma.org](http://www.myeloma.org) and click on the Advocacy tab.

One of the events that helps make IMF programs and services possible is the Annual Comedy Celebration benefiting the Peter Boyle Memorial Fund. More than 1,200 guests congregated at Los Angeles' historic and elegant Wilshire Ebell Theatre & Club on November 7 to raise money in support of the IMF. To read more about it, please see the special supplement to this issue of Myeloma Today.

As always I welcome your thoughts and comments. The IMF would not be where we are today without your belief in and support of our programs.

Warm regards,

Susie Novis