

## A Message from the President

**Dear Reader,**

In 1998 we went to Washington, DC, to participate in "The March," the first big grassroots cancer event to take place on Capitol Hill. More than 100,000 advocates representing every cancer joined together on the Mall -- with about 400 representing the IMF and the myeloma community. We spent a very hot afternoon, under a blazing sun, listening to speeches by Cokie Roberts, Queen Noor of Jordan, Sam Donaldson, and Al Gore, to name a few. It was a seminal moment for me personally and the cancer community at large. That was the spark that led to the five-year doubling of the budget of the National Institutes of Health (NIH). It was also the birth of the IMF's advocacy program.

Greg Brozeit led our team as IMF Advocacy Director. We soon joined a broad range of groups representing the interests of the cancer community in Washington. This included One Voice Against Cancer (OVAC), the Cancer Leadership Council, the National Coalition of Cancer Research, and C-Change (formerly the National Dialogue on Cancer). We worked hard to ensure that the myeloma community was represented in the health debates taking place in Washington.

In 2002, the IMF, along with 40 other cancer organizations, all of whom belonged to OVAC, came together as a unified force to convey one important message to Congress: "Give the war on cancer the funding it needs." I had been asked to represent OVAC and testify on behalf of the entire cancer community before a major Senate hearing. Testifying along with me were Dr. Huerta, Dr. Heberman, brain cancer patient Mike Bruene, and Steve Case, Chairman and CEO of AOL Time Warner.

It was a humbling experience knowing that I was representing not only the IMF, not only the cancer community, but everyone who suffers from any disease. My role on the panel was to request funding for the NIH, the National Cancer Institute's (NCI) Bypass Budget, and the Centers for Disease Control and Prevention (CDC) cancer programs.

Since then, the IMF has continued to represent the concerns of the myeloma community to policy makers. We have fought for such issues as Medicare coverage of drugs with offlabel indications (like thalidomide), as well as Medicare coverage of PET scans. Both

of these important initiatives came to a successful conclusion.

IMF advocacy now takes on a new significance. The Obama administration has made health care reform its highest priority. Regardless of our political leanings, our community must be represented in this debate. As always we are here for you, to listen to you, and to advocate our community's concerns to all our political and governmental leaders and representatives.

Most importantly we need you! This is about your future and the future of all the patients yet to be diagnosed.

Be informed and get involved! The IMF's Cancer Patient Statement of Principles (see page 18) will guide us through this process. On our website, you'll soon find a new section devoted to advocacy.

This is a rare time in American political history. We intend to ensure that our voice is heard and acted upon, that the myeloma community is represented when policies have an impact on us. We intend to do this work with you and for you.

Susie Novis