

News & Notes

The content for the News & Notes section of *Myeloma Today* is drawn from a long list of publications based on inquiries received by the IMF Hotline and the interests expressed by our readers.

AOSW survey shows cancer costs negatively impact focus on recovery

A survey conducted by the Association of Oncology Social Work (AOSW) demonstrates that financial hardships often complicate or compromise a patient's battle against cancer. Money issues reduce patients' compliance with their cancer treatment even though treatment is key to their recovery. According to the study, 87% of patients with catastrophic/major financial burdens due to cancer treatment say costs have a negative impact on their ability to focus on recovery, 68% of patients experience financial hardship due to medical bills, 66% of patients with major financial challenges suffer depression/anxiety, 55% of patients surveyed say the stress of dealing with costs negatively affects their ability to focus on their recovery, 54% of patients and caregivers with a major/catastrophic financial burden said that it has become more difficult to afford treatment for cancer in the past year, 40% of patients reported depleting their savings, almost 30% reported dealing with bill collectors, 29% of patients delay filling prescriptions due to financial pressures, and 22% skip doses.

The survey results of interactive datasets are part of an ongoing effort by the AOSW to increase understanding and support for people with cancer and their families. Although most patients report experiencing cost-related psychosocial stresses that social workers are adept at helping manage, only 34% of patients surveyed report actually utilizing a social worker as a resource. In fact, only about half feel comfortable speaking with health professionals about financial issues. Study findings show that nearly all cancer patients, including those with blood cancers such as multiple myeloma, consider effectiveness before all other factors when determining their treatment plan and rank the cost of treatment last in their decision making process when initially diagnosed. Study statistics were based on 169 cancer patients, 131 caregivers, and 153 social workers. Patient and caregiver results are presented in aggregate. The survey was developed by Kelton Research in conjunction with Millennium: The Takeda Oncology

Company under the guidance of the AOSW.

For more information, please call the IMF at 800-452-CURE (2873). Our Hotline Coordinators are here to answer your questions and help guide you to available resources. CancerCare's new "Door to Door" initiative, which offers grants to individual patients with myeloma to help with costs of transportation to and from medical care, is detailed below. The IMF is also actively involved in advocacy efforts that bring the voices of the myeloma community to the current debate on health care reform and related issues.

Possible genetic link between environmental toxins and myeloma

Newly published data may provide a possible genetic link between environmental toxins and bone disease, the characteristic feature of multiple myeloma. Once considered a "rare disease of the elderly," myeloma is increasingly being diagnosed in patients under 45 years old, including some of the early responders to the 9/11 World Trade Center site. Now a published study may help explain why.

The study from researchers with the IMF gene bank, Bank on a Cure®, identified several changes in DNA sequences called SNPs (single nucleotide polymorphisms) that are associated with a risk of bone disease in myeloma. Further analyses showed that many of these DNA changes may be involved with the way the human body responds to certain environmental toxins, providing a possible link between myeloma and the environment. The findings were published in the journal *Leukemia* on August 6, 2009.

Dr. Brian G.M. Durie, lead author of the study and Chairman of the IMF said: "This is a hypothesis-generating study. While the functional role of many SNPs is still uncertain, this study is supportive of the notion that genetic factors affecting toxin breakdown may be related to the development of myeloma. This gives us an important starting point for further studies."

The findings may help explain a widely reported study in the *Journal of Occupational and Environmental Medicine* that found more cases of myeloma among younger responders to the 9/11 World Trade Center site than would normally be expected. The findings are also supportive of a study published earlier this year that suggests a link between certain pesticide exposures in agricultural workers and a precursor to myeloma.

Previous studies have also shown an increased risk for myeloma among firefighters, and the IMF has issued guidelines for firefighters for the prevention and treatment of this disease.

“Multiple myeloma is not a familiar cancer to patients or even to many doctors, but taken together, these studies say it should not be overlooked,” said Susie Novis, President and Co-founder of the IMF. “While multiple myeloma cannot be cured, it can be treated with new, targeted therapies including REVLIMID®, VELCADE® and THALOMID®. These studies tell us it is critically important for medical practitioners to know the possible risk factors for myeloma along with the early warning signs so they will be alerted to test for it.”

The importance of bone marrow examination in determining complete response

Dr. Cheng E. Chee and colleagues from Mayo Clinic in Rochester, MN, have studied the importance of bone marrow (BM) examination in determining complete response (CR) to therapy in patients with multiple myeloma. The current definition of complete response in myeloma includes a requirement for a BM examination showing less than 5% plasma cells in addition to negative serum and urine immunofixation. There have been suggestions to eliminate the need for BM examinations when defining complete response. The investigators evaluated 92 patients with myeloma who achieved negative immunofixation in the serum and urine after therapy and found that 14% had BM plasma cells more than or equal to 5%. Adding a requirement for normalization of the serum-free light chain ratio to negative immunofixation studies did not negate the need for BM studies; 10% with a normal serum-free light chain ratio had BM plasma cells more than or equal to 5%. It was also found that, on achieving immunofixation-negative status, patients with less than 5% plasma cells in the BM had improved overall survival compared with those with 5% or more BM plasma cells. This information is very helpful in assessing the best ways to implement response criteria within ongoing clinical trials.

Study confirms association between ESAs and DVTs or PEs

A study published by the Journal of the National Cancer Institute has confirmed that erythropoiesis-stimulating agents (ESAs), such as Procrit® (epoetin alfa) and Aranesp® (darbepoetin alfa), are associated with an increased risk of deep vein thrombosis (DVT) or pulmonary embolism (PE). The association between ESAs and venous

thromboembolism was observed in previous meta-analysis but the new finding is significant because the data is from community clinical settings, not a short-term study. The new analysis included data from more than 50,000 patients aged 65 years or older, including those with more advanced cancer or high-risk status, who therefore might not have been candidates for clinical trials. Results demonstrated that more patients who received an ESA developed DVT or PE, compared with patients who did not. Overall survival was similar in both groups.

Novel proteasome inhibitor shows promise

A recent study demonstrated that a novel proteasome inhibitor NPI-0052 triggers apoptosis in multiple myeloma cells resistant to bortezomib (Velcade®). In a laboratory setting, combining NPI-0052 and lenalidomide (Revlimid®) was shown to induce synergistic anti-myeloma activity in vitro using myeloma cell lines or patient cells. In animal tumor model studies, low-dose combination of NPI-0052 and lenalidomide is well tolerated, significantly inhibits tumor growth, and prolongs survival. Taken together, the study provides the preclinical rationale for clinical protocols evaluating lenalidomide together with NPI-0052 to improve patient outcome in myeloma.

CancerCare launches “Door to Door” initiative

CancerCare’s new “Door to Door” initiative provides grants to individual patients with multiple myeloma to help with costs of transportation to and from medical care. The grants of up to \$600 per year cover costs such as car fuel, taxi, bus, or train fare. The program is funded in part by a generous grant from Millennium: The Takeda Oncology Company.

Founded in 1944, CancerCare is a national non-profit organization with a track record of providing financial assistance to people facing cancer. In 2008, CancerCare launched a separate organization, the CancerCare Co-Payment Assistance Foundation, to help cancer patients cover the cost of their health insurance co-payments for certain types of treatments.

To receive a “Door to Door” transportation grant, patients must meet eligibility criteria and complete an application form. To obtain an application, please visit www.cancercare.org or call 800-813-HOPE (4673).

AMEN Scientific Advisor is co-recipient of a 2009 Nobel Prize

The 2009 Nobel Prize in Chemistry is shared by researchers Ada Yonat, Thomas Steitz, and Venkatraman Ramakrishnan for their work on the atomic structure of the ribosome. Dr. Yonat is the first Israeli woman to be awarded a Nobel Prize. She is a professor at the Weizmann Institute of Science and is a member of the scientific advisory board of AMEN, the Israeli Association of Myeloma Patients. AMEN translates IMF materials into Hebrew and disseminates them to the myeloma community in Israel, sets up support groups, and participates in conferences focused on myeloma education and research. Dr. Yonat is actively involved with the organization and has never missed an anniversary meeting of AMEN. The IMF joins AMEN in congratulating Dr. Yonat and her colleagues for their impressive achievement.

RSS feed now available

A new look and a new feature are now available from the same trusted source of information for the National Cancer Institute (NCI) Center for Cancer Research (CCR) clinical trials at the National Institutes of Health (NIH) in Bethesda, Maryland. You can sign up to receive the RSS information feed by visiting the <http://bethesdatrials.cancer.gov> website and clicking on the orange RSS button near the upper right corner of the page. CCR conducts more than 150 clinical trials at the NIH. While on the Home Page, clicking on the “All cancer types” link will take you to a page where you can select “Multiple Myeloma” from the list of diseases to narrow your search for information of interest to members of the myeloma community. **MT**