

## PRESS RELEASE

### **Myeloma treatment side effects need more attention from physicians and patients**

Berlin, 8 December 2009 – For myeloma patients, fatigue, malaise, weakness, dizziness, somnolence, sedation and insomnia constitute the most frequently experienced myeloma treatment side effect and the one that has the most negative impact on a myeloma patient's overall well-being. This is one of the findings from a recent international comparative survey conducted between February and July 2009 by Myeloma Euronet, the European Network of Myeloma Patient Groups<sup>1</sup>.

The survey of 314 healthcare professionals and 260 myeloma patients, patient relatives and caregivers, mainly from European countries, also revealed that about one in four patients felt they were not appropriately informed by their doctor about potential side effects of myeloma treatment options.

About one-third of patients also complained they were not satisfied with how their doctor has managed any side effects experienced during myeloma treatment. Equally, about one in three physicians was not satisfied with how myeloma patients manage the side effects they have experienced.

According to physicians and patients surveyed, reasons for not being satisfied include difficulties in treating myeloma and treatment side effects as well as lack of information, time, continuity, responsiveness, interest and competence.

"Treatment-related side effects can have a major impact on a myeloma patient's course of treatment," said Anita Waldmann, President of Myeloma Euronet. "This survey has found that doctors often have to modify dosing because of treatment side effects, which might in turn have an effect on overall treatment outcome."

The survey has also confirmed that there are a number of treatment side effects patients don't feel comfortable reporting to their doctor, including sexual problems, diarrhea, constipation, gastro-intestinal problems, psychological problems, jaw problems, tiredness, and fatigue. "We encourage all myeloma patients not to be shy or feel embarrassed but to openly address any treatment-related side effect with their medical team, and we also hope that healthcare professionals will focus greater attention on this issue in the future," Anita Waldmann concluded.

Findings from this survey also confirmed that there are still a number of areas where the needs of myeloma patients in Europe are not fully met, including, but not limited to, emotional and psycho-social support, access to information and support, and access to novel treatments.

The survey was made possible through an unrestricted grant from Ortho Biotech, Biopharmaceutical Division of Janssen-Cilag.

Myeloma Euronet, a Belgian-registered international non-profit organisation of more than 40 multiple myeloma patient groups and representatives in 20 European countries, is dedicated to raising the awareness of multiple myeloma, an increasingly common form of bone marrow cancer. Myeloma Euronet provides information on the diagnosis, treatment and care of persons living with multiple myeloma and supports its member organisations in the fulfilment of their missions. Myeloma Euronet also advocates, both independently and in collaboration with organisations with similar objectives, on behalf of those affected by multiple myeloma.

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#### References:

- <sup>1</sup> The full survey report is available for download at <http://myeloma-euronet.org/en/survey/index.php>