

# **Overview of the EMP-agenda at ASH in San Francisco December 6 – 9<sup>th</sup>, 2008**

## **1. EMP booth**

EMP had a nice booth in the non-profit area.

2 big EMP posters caught the eye. On the table, visitors could find information leaflets about EMP and its member organisations in different languages.

Every day, our visitors were treated with fresh, crispy cookies!

It was nice to see the interest in our booth from various sources: the doctors, scientists, the pharmaceutical companies, other patient organisations,... Many questions were asked about our organisation, our activities and the role our organisation plays in the field of health care. I tried to be present in every free moment but was also absent regularly because of the meetings or the presentations.

For EMP, it was important to have a booth at the ASH: we had visibility, we provided information to the visitors, it was a good meeting point and for me also an “oasis” or a place “home” in the huge crowd of the ASH.

## **2. Ortho Biotech Meetings**

### *Patient Breakfast Meeting:*

Although early, I am glad I attended it. It was a good occasion to meet other patient organisation representatives, many of them representing other blood cancers (leukaemia, lymphoma). A few organisations also represented MM.

- First Dr. Jesus San Miguel gave a very good overview of the presentations that were going to be given at the upcoming ASH meeting and of interest to the representatives of the MM patient groups. We also got the occasion to ask him a lot of questions on the medical and scientific part of these presentations. That was something I really appreciated very much as during the “real” presentations, being a non-medical person one cannot ask any questions to the speakers. So, for me that was a very valuable part of the meeting.
- Afterwards, there were some presentations from the companies which were more product oriented (Velcade and MLN 9708, one of the new generation proteasome inhibitors).

- Finally there was an interactive Panel Discussion between the patient organisations on the subject of advocacy. The main topics that were addressed in this discussion were:
  - Patient education and the tools to do this
  - Fundraising
  - Advocacy on the level of health care authorities

It was interesting to exchange ideas on those topics. But it is very clear that the “local” environment a patient organisation works in is very different in every country, the way you negotiate with the authorities is very different from one country to another, you can not apply the same kind of fundraising in all countries... There lays also the challenge for an umbrella organisation: to deal with so many different mentalities, law systems, political structures...

### *Meeting on QoL (Quality of Life) Survey*

After the breakfast meeting followed a smaller meeting with Mark Krueger, representatives of Ortho Biotech, Anita Waldman (Myeloma Euronet), the Spanish group representative and myself on the Quality of Life Survey. QoL is becoming increasingly important in MM as with new treatments, patients live much longer with the disease. Some of the MM patient groups (like ours) had already done some research on the QoL among their members. It was suggested that it would be interesting to compare the data of these studies, done by the different organisations and to combine them in a document that could provide useful information for several stakeholders, active in the field of MM. Mark Krueger will make a resume of the meeting and send it to us before further steps are taken. Nothing has been decided yet and the initiative is still open for comments...

### **3. Other contacts:**

The ASH meeting was a wonderful occasion to meet and to network with other organisations, active in the field of MM.

Communication with other MM- patient organisations such as the IMF (International Myeloma Foundation) is really a must in our activities. The MM-patient, worldwide, will for sure benefit from the interaction between the different organisations.

The contacts with the other patient organisations at the ASH were for sure a good base or starting point to build on further communication and co-operation.

#### **4. The scientific presentations on MM**

I went as much as possible to those presentations, because of personal interest and because I wanted “to bring home” the news on MM treatments.

This year it was not possible to attend them all because of the appointments and the booth representation.

Generally, we can say that the studies, presented at this meeting confirmed many positive and interesting results that were presented at last years' ASH-meeting (see my report of ASH 2008). It is an exciting time in the field of treatment of MM.

Remarkable was that doctors and scientists are more and more pronouncing the word “cure”. That is definitely the heading we are taking in the matter of treatments, although we are not yet there.

But, I confirm that the horizon is brighter and brighter and a lot of sun breaks through the clouds (hence our beautiful symbolic picture on our website!!).

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Greetje Goossens  
December 2008