

22nd Annual DIA EuroMeeting, March 8-10, 2010, Monaco

Testimony from Greetje Goossens, European Myeloma Platform

On a cold, dark December day, a mail from Maureen McGahan, the DIA EuroMeeting Programme Coordinator, brings me some sunshine. The message says: You are granted a fellowship for the DIA EuroMeeting taking place from March 8-10, 2010 in Monaco!

A few months later on March 7th, I fasten my seatbelt and prepare for landing at Nice airport. I look through the plane's window and see a choppy Mediterranean sea under a cloudy, packed sky. Where is the famous southern spring?

I don't care: this is not a tourist trip! I am going to the prestigious DIA EuroMeeting in order to learn, to exchange knowledge, experience and to meet interesting people, active in the field of healthcare.



Outside the airport, friendly hostesses lead me to the waiting DIA shuttle bus. I am well taken care off. This gives me already a first taste of the good organization and structure of DIA. In the bus: one known face: my good friend Richard West, the patient representative of the Behçet's Syndrome Society.

I also chat with other passengers on the bus: many are representatives from Industry and from Regulatory Authorities. All are very interested and enthusiastic when they learn about the participation of patients at the conference.

After being settled in my very comfortable room, I go once again through the programme of the coming days. It is a tight, intensive but exciting one!

The programme starts the same evening with a Patient Fellowship Welcome Reception. More than 40 patients' representatives are invited. I see lots of old friends and meet some new one's. In general, not a lot of words are needed to get connected with other patients' representatives and to be on the same wavelength. It is good to see the EURORDIS staff: Maria Mavris, Ariane Weinman and Michele Lipucci. It was EURORDIS who supported strongly the development and promotion of the patients' Fellowship, entering now its fifth year.

To my pleasant surprise, the DIA Board of Directors is present at this reception. For me, this shows that our presence is valued and appreciated. We had the occasion to talk to several DIA representatives who were quite interested to learn more about patient advocacy activities.

The next day: no time to enjoy a lazy morning at the Monaco marina. The tutorial starts at precisely 9am! As patient representative on the fellowship programme, we were offered a free tutorial. Hmm, not so easy to make a choice between 21 captivating tutorials that can provide me with a solid background in the PO work. Finally, I decided to go for the HTA (Health Technology Assessment) session, a very current subject that would give me more insight in the decisions of Regulators when it comes to access to treatments and medicines.

A very *nice* lady, Kym Alwick, who closely collaborates with *NICE*, (National Institute for Health and Clinical Excellence, UK) initiates a heterogeneous audience in the (for me) mysterious word of HTA. My fellow students are PO-colleagues, industry representatives and even regulators! We learn about economic modelling, healthcare technology, technology assessment, incremental costs and QALY's, ICER's,...This sounds like Chinese to you? Not to the fellowship patients anymore! The mysterious HTA world releases little by little its secrets and it appears to be a fascinating world! This gives a taste for more!

The lunch is a perfect networking occasion. Afterwards, it is time for the official Opening Plenary Session, followed by the parallel sessions. Again: “*l’embarras du choix*”! So many interesting and useful topics to choose from. I head for the “The Informed Patient” sessions. These sessions cover broadly the use and provision of information on medicinal products to and by patients and all aspects that are connected with this topic. Again, the audience is very heterogeneous and attracts many different stakeholders in the field of healthcare. It is a perfect platform to exchange ideas, experiences and to discuss.

A huge Mediterranean Networking Reception at the Fairmont Hotel finalizes this intensive and interesting day. I am quickly lost in and absorbed by the big crowd and meet many new interesting people. I bump into some representatives from Regulatory Authorities of my own country Belgium. People I talked already with on the phone in the past but whom I had never met in person! Next, I get in touch with EMA (European Medicines Agency)-representatives and meet some known faces from the Pharmaceutical world! All are very enthusiastic about the patients’ representatives’ presence and input. After the reception, the fellow patients meet at a cosy restaurant for good food and a relaxed evening. We laugh a lot and enjoy our time together!

I am thrilled by my first day at the EuroMeeting but also exhausted! The sound of sea waves in my room is a perfect lullaby for a recovering night.

Next morning, I start again with “The Informed Patient” sessions, which give a further deep insight in the subject of communication on medicinal products and the related challenges and barriers. During the coffee breaks I stroll through the exhibition area. Again, this a perfect place to meet up with other healthcare partners. An oasis in this busy event is the “DIA Patient Fellowship” booth. This is our place home at the conference! A place to unwind and to catch up with other patient fellows.

At noon, all fellow patients meet at a patient working lunch.

In the afternoon, I venture out to other – specialised – sessions: I explore the EMA Road Maps, followed by a session on Transparency from Clinical Trials, where “our” Maria Mavris gives a (very good) presentation.

On the evening of our second conference day, the patient representatives are the VIP’s at the *invitation only* DIA reception. During this nice evening, we meet with other interesting people: a fine and distinguished selection of various stakeholders of the healthcare world. By the end of the evening, many of us run out of business cards and voice, but return to the hotel with new inspiration, some new projects and an agenda with new appointments.

Our last day (already!) starts with an early patient representative’s breakfast meeting, in the company of Richard Day, the future president of the DIA EuroMeeting in Geneva. The feedback from the participants on the past days is very positive. All of us much appreciated the instructive part of the meeting as well as the networking possibilities. After the meeting, some of us already have to leave; others catch another learning session of their choice before departure.

After the lunch break (delicious, especially the desserts!), I man the DIA Patient Fellowship booth for 2 hours as our EURORDIS colleagues had to leave. Some visitors pass by with questions on the fellowship programme, others with positive feedback on the patients’ input during the meeting. Finally, I decide to wrap up and to enjoy a little stroll through the beautiful streets of Monaco. Streets, full of VIP’s in nice cars and with a smile I look back at our VIP position as patients at the past DIA EuroMeeting.

I fly home with a lot of “extra luggage” (luckily invisible to the airline company!) of knowledge, experience, useful contacts and new friends.

With this opportunity, I really would like to thank all involved in the organization of the Fellowship Programme for this unique experience!

Greetje Goossens