

Summary of seminar:

Strengthening Patient Groups in the European Union

On 26 and 27 November 2004 I took part in the above mentioned seminar in Brussels as a representative for Enusp. It was very well organised by the European Patients' Forum, EPF, in co-operation with the European Federation of Pharmaceutical Industries and Associations, Efpia.

About 75 participants stayed in the Renaissance Hotel, Rue du Parnasse 19. All were delegates of patients (clients) organisations. People from Hungary, Slovenia, Czech Republic, Denmark, Estonia, Romania, Bulgaria, Belgium, Slovak Republic, Germany, Malta, Poland, United Kingdom, Norway, Lithuania, Spain, Cyprus, Sweden, Latvia, Ireland, Russia, Switzerland and the Netherlands were present.

They were representing for instance a diabetes organization, a cancer organization, a haemophilia consortium, an association of Asthma patients, a mental health organization and so on. I missed for instance a Parkinson delegate.

Introduction to the EU

On Friday morning participants got an introduction to the European Union. We were scanned at the visitors' entrance of the Spaak Building. There were a lot of other visitors too. Erica Poot and Amelia Kossi guided us through the building. I met Liz Winder, another representative of Enusp. We received information about the work of the European Parliament.

We met among others Ms. Frederique Ries, member of the committee on the environment, public health and food safety. She told that people in the street do not yet understand how important the European Union is. About 80 percent of the legislation of EU countries is made here. A huge amount of work is done here to make a better life environment for all Europeans. It is her frustration that the press seems to be not so very much interested.

We went along and visited the public gallery, which is always open to the public to attend meetings of the European Parliament.

We enjoyed a nice free lunch in the visitors centre.

Funding your organisation

Friday afternoon. According to Brian Ager, Director General of EFPIA, Europe is missing a genuine patients' voice. "Let us put patients in the centre", he said. To do this, practical aspects are to be viewed today. Rodney Elgie, President of the European Patients Forum, thanks Efpia for funding. Without funding this event would not be possible.

The EPF (European Patients Forum) should be seen as an answer to repeated calls by the European Commission to have a point of reference; a patient body to address and be consulted on issues concerning healthcare.

That is why the EPF is created. Now we have to work on sustaining and growing. To do this, funding is essential.

How to fund activities (projects)? Bernard Merkel, Head of the unit in the European Commission responsible for health strategy, calls for proposals under the EU Public health program, which runs from 2003-2008. The European Commission does not fund organisations. The commission only funds projects!

A proposal must be related to the European workplan, so look at their workplan. You can find it on internet. The next publication of the workplan will be about January 2005. You have 3 months to react on this.

To get the activity funded there are the following criteria:

1. european added value
2. sustainable results and outputs
3. large scale projects
4. support public health policy developments
5. quality project management...and so on.

Rose Omondi, development officer working with the European Citizen Action Service, wrote a book about how to find your way through the labyrinth: "EU funding for NGO's (non government organizations) in general".

European Funding is up to a maximum of 80% a year, non profits only and for 3 years. What else can the European Commission do? Sponsor a health forum? Provide facilities? Participate in events? Yes, if it has clearly a European end. For the other 20%, the cofunding, you can ask for instance members, family, church, municipalities. Sell your idea. And when the project is going on, do not forget the followup. Write about it and thank your donors.

Thanks to Ludwig Forrest of the King Boudewijn Foundation we now are aware of the fundraising fundamentals.

After the coffee break we witness a way of fundraising which is very lucrative. It is called Telethon. Jacques Rognon of the Swiss foundation "Fondation suisse de Recherche sur les Maladies neuromusculaires" shows us with images on a screen how it worked in France and Switzerland. A television program lasting 24 hours with stars and patients and a lot of people on the telephone to note down the gifts of the public watching television.

We go on with listening to the next speaker, a delegate of the LMCA, the Long term Medical Conditions Alliance. We receive a booklet, titled: "Working with the pharmaceutical industry". It contains guidelines for voluntary health organisations on developing a policy. It is written by Judy Wilson and based on the work of an LMCA working group.

In the evening we enjoy a nice free diner at Restaurant Le Falstaff.

Developing media skills

Saturday morning I take part in the workshop: "Developing media skills" Derek Moloughney, executive trainer, gives us a lot of good advice on good communication. Such as: Build up relationships with key journalists, one to one. They are partners in good communication.

It is important to have some informal talking before a formal interview, the so called "briefing". Do the briefing a week before. Ask on the telephone: why do you ask me and who did you ask before? Ask him what he is interested in.

Give a clear message during the interview and check it afterwards. Only talk about your expertise, otherwise say: "That is not about my expertise". In silences say: "Does it answer your question?" Do not use words which does not say much, like: added value, quality, forum. Do not say: well, I think or I believe if you are convinced.

Say: I am convinced. Give 2 or 3 messages with examples. Keep it Simple and Short(kiss).

Perhaps answer on the following questions:

1. What is the issue, problem?
2. What are you doing about it?

Mental health legislation is based on public opinion. It is important to prepare yourself well in advantage. If a question is not interesting for you to answer, make it a short answer and "bridge", go to your message, logical or not. Illustrate your message; give examples. Think: it is my interview. Use active words like: we are creating, not words like: we hope, we think.

Pay attention to your nonverbal behaviour. Do not be submissive. You are there and you have the right to be. Do not speak too fast. Create pauses. Be aware of having a message.

You can stop an interview at any time. Do not forget the debriefing afterwards. Check whether your message got accros.

Derek is now doing 2 practical individual exercises with participants, which are filmed and evaluated.

We enjoy a nice free lunch.

Strengthening your organization

Saturday afternoon. My program says it was about strengthening your organization. How to analyse your own organization. It is called a SWOTanalysis: Strenghts, Weaknesses, Opportunities and Threats. My paper mentions the name of Balazs Sator, trainer of the Civil Society Development Foundation in Hungary.

Within your own organization it is important to divide tasks. It can be wise to have the members of the board and staff undersign a "job description" (subscription of their tasks).

I remember there was a story told about an ugly duckling who one day realised that he was a swan. It is possible to feel like a big duck. All about self esteem.

According to my paper Francois Houyez, projectmanager of Eurordis, European organization for rare diseases, talked about creating patient group informationservices. Mick (not James) Bond (not Jagger), volunteer at the Multiple Sclerosis International Federation, talked about developing a national patient group. But at that time I had allready gone.

In the evening we enjoy a nice free dinner at Restaurant Les Brigittines.

It was useful and pleasant. Thanks to Efpia and EPF.

Heleen van der Leest