

Report board meeting Copenhagen, 25-26 Nov. 2009

TOUR OF THE CLINIC

We started with a very interesting tour through the PTU clinic and offices. You can read about this in a separate report. We met a PTU doctor (urologist) Lise Kay, who has PPS herself and she told us about the work she is doing there. We also met Holger Kallehauge, for 36 years the chair of the PTU's polio patients organization. He is retired high court Judge and polio survivor.

CONFERENCE 2011

The date: Wednesday 31 Aug, Thursday 1 Sept and Friday 2 Sept 2011.

PTU is willing to appoint somebody from the organization to work on the Conference half time, starting from Jan. 4th, 2010. This needs to be funded. Philip hopes that the Danish Rotary will pay part of the conference costs (estimate total conference costs: 200.000 euro).

PTU has a full time fundraiser and Philip thinks he can bring in more money for the conference.

Proposal: 1 day for medical people, PTU can host this. And 2 days for polio survivors, with lectures, workshops etc. There will be no specified subject to the conference, but it will cover different subjects, so it will attract more people, because everybody will find things of their own interest. The language will be English, but there must be interpreters. Estimated costs: about 4000 euro per language. Suggestion: let every country raise the money that is needed for the interpreters for their own language (for their own members).

Two people from the Danish Rotary joined part of our meeting. Philip tells the Rotary that working together on this conference can be of benefit to Rotary and to the EPU(1+1 makes 3). Rotary is focused on eradication of polio and PPS people can show what happens when you do not vaccinate and get polio and PPS. Rotary is convinced that working together is beneficial to both and will discuss this at their big Rotary meeting in December.

AGM 2010

The Italians made a detailed plan for this meeting. It will take place in Malcesine, Italy (Lake Garda), 23/9 – 27/9/2010. The program this year is longer, because it is combined with a conference (open for all Italian members and others). It starts with a dinner on 23th; AGM on 24th in a spectacular place up a mountain; the 25th and 26th Sept a conference: "Polio and PPS: pharmacological expectations and rehabilitation needs" with also the results of the gammaglobuline research. The Italians are already very busy organizing this event and trying to get funding for it.

WEBSITE

The site had a lot of hits, more than 50.000.

The first language stays English, but it is important to have more things translated in other languages: Spanish, Italian, German, French.

Proposal: for now this will be done by Italian: Vanda, French: Johan, German: Simon, Spanish:?????

This means that when there is a new text in English, it will be send to these people for translation.

OTHER BUSSINESS

Of course we talked about many other things, like for example:

The new version of the leaflet, board matters, the financial report and meetings we attended.

Els went to Brussels to the EFNA AGM. There were some nice lectures about Counterfeit Medicines, Patient Advocacy and Health Technical Assessments, Patient and medical organizations in partnership at the European level (by EFNS). The EFNA chair Mary Baker reported about their activities in the last year. And of course there was the usual AGM stuff. It is a very nice group of people and very helpful. Els asked Mary Baker to introduce her (the EPU) to the Medtronic Foundation, in order to see whether they will sponsor one of our activities.

NEXT MEETING. The board will meet in Madrid, March 12-13, 2010. Lola will be our guest.