

HIV Europe

A network of organisations



Minutes of the fourth meeting of HIV Europe
held in Rome
at Hotel Villa Eur on April 8th and 9th 2006

Hosted by NPS Italia Onlus
Italian Network of People Living with HIV / AIDS

This meeting was funded by NPS Italia Onlus

Present:

		Organisation
Henrik Arildsen	Chairman	HIV Denmark
Rosaria Iardino	Host agency	NPS Italia Onlus
Marcella Ferraci		NPS Italia Onlus
Corrado Valvo		NPS Italia Onlus
Margherita Errico		NPS Italia Onlus
Peer Aagaard		HIV Denmark
Bernard Forbes		UKC
Wojciech Tomczynski		SIE'C PLUS
Per Miljeteig		HIV Norway
Leila Vaananen		Positiivset ry Munkkisaarencatu
Ritva Karjalainen		Positiivset ry Munkkisaarencatu
Andreas Berglof		Swedish Association for HIV Positive People (RFHP)
Lars Lindberg		Swedish Association for HIV Positive People (RFHP)
Caroline Suter		Aids-Hilfe Schweiz

1 Apologies for absence

Apologies were received from Inger-Lise Hognerud from HIV Norway who had been unable to get to the event due to air line disruption.

2 Opening and welcomes

Rosaria Iardino welcomed participants on behalf of the hosts, NPS Italia. In turn Italy was thanked for the glorious weather and the calm and peaceful venue.

3 Declarations of interest

Peer Aagaard declared that he undertook a small amount of professional work funded by pharmaceutical companies.

4 Potential new member organisations

As part of the discussion, it was agreed that there was a need for some kind of application criteria and process, either an inclusive or exclusive process. It was agreed that HIV Europe should write to prospective members identified to ask if they were interested and get them to fill in an application form.

Since the meeting in London, some time had been spent trying to identify appropriate new member organisations. These were presented as follows:

1. ACTUA, Barcelona

This organisation was known to NPS. Agreed – need to validate their representative nature through more questions

2. ARAS, Romania

Known to SIE'C Plus and RFHP, work with children and adults, but unknown how PWA oriented they are.

3. Lisbona Associazione Sol

Not HIV specific – needs more information.

4. Estonian Organisation for PWHs

Known to Poisiiviset, unknown how PWA oriented they are.

5. AGIHAS Latvia

Known to SIE'C Plus. Reservations expressed as to size, focus and representative nature of this group.

6. Croatian Association for HIV

Need to enquire further (website at www.huhiv.hr)

7. Positivo, Portugal

Andreas had me with them and discussed membership. Details -

Addresses:

Street of São Paulo, nº 216, 2º Esq, room, 1200 - 429 Lisbon

Telef.: 21 342 29 76 Fax: 21 342 43 46

email: positivo@netcabo.pt

Agreed as appropriate members.

8. Moldova

Agreed need to write to them, in Russian if necessary, to find out more information.

9. All Ukraine Network of PWAs

Agreed as appropriate members. (website <http://www.network.org.ua>)

Process in future

It was agreed that Henrik as Chairman should write or email potential new members. Then if the Steering Committee decides that applicants are credible, they should be invited to attend the next meeting of HIV Europe to meet the existing membership and consider if they are appropriate / want to be partners.

It was noted that there was opportunity to meet some of the groups at the UNGASS meeting in New York at the end of May.

5 Taking the London meeting forward

1. Website

Bernard reported that the website at www.hiveurope.org was registered and a holding page in place waiting for content.

Agreed –

Member country organisations should have their own web page for that country

The steering committee should have a section

Member pages should be in English and the language for that country, plus general information about HIV Europe in the language of that country

Some kind of content management system was required, Bernard suggested Mambo (for which there is also a discussion board component) which would allow individuals to have their own log on and ability to edit their own pages.

Agreed –

Need a deadline for launch of the website – suggested prior to Toronto conference, but the main issue was to get something onto the website and then let it grow.

Deadline of July for all to place web pages about member organisations with information about them (in English and the local language) and links to their own websites.

Content will follow with issues provided by members, responsibility laid with members to ensure it is updated. The website also needed to address questions/suspensions about HIV Europe.

2. Logo

Lasse had sent suggestions for a logo to the steering committee. Of the selection available, the second option was accepted and agreed for future use.

6 EU funded project on positive prevention

A draft outline proposal paper had been prepared by UK Coalition. It was accepted that the draft lacked specific mention of IVDU's or women.

The outline proposal was discussed at great length. Some members had concerns over the audit requirements that came with accepting EU funding – UKC [and some other members] had been doing this for years and were confident that existing systems could cope with it as any bid had to have the audit provisions built in as part of the management costs. Members agreed to see this as a way of developing HIV Europe if possible.

UKC were asked to make the project as inclusive as possible and then to ensure proposals include –

- IVDU and women's issues
- GIPA within a policy making context
- Promote the rights and interests of plwha
- Migrant issues

The final proposal would be worked on by UKC on the basis that UKC would lead on the project and request country partners to put forward information and ideas towards the overall plan. Timescales meant there may not be time for a revised outline to be produced before the bid had to be submitted. Members agreed to present the draft proposal and the content of the discussions to their boards in country to get sign up to the proposal.

7 Relationships with the pharmaceutical industry

Henrik had circulated a paper in advance of the meeting. The paper was the model of ethical guidelines under which HIV Denmark operates.

On the basis that HIV Europe has already accepted pharmaceutical sponsorship (Brussels, Copenhagen and London meetings, but not Rome) it was agreed as important to discuss this policy. In connection with the London meeting, Henrik had spoken with GSK's Positive Action (whom Wojciech was sure would support a meeting in Poland) to clarify the issues over not funding London.

On the basis that independence is maintained, that transparency is important, and that participants in meetings declare any conflicts of

interest, most members' countries were having reviews of pharmaceutical company sponsorship (UK, Sweden, Switzerland and Italy were all cited).

There was discussion of difficulties experienced by some members with pharmaceutical companies wanting to push their own agenda, alongside others who had difficulties obtaining recognition, let alone funding, from the industry.

After debate it was agreed that HIV Europe would adopt the guidelines.

In connection with problems described by NPS Italia regarding Tibotec, those present agreed that “we, HIV Europe, acknowledge the work of NPS Italia as members of HIV Europe”.

8 UN General Assembly high level meeting New York

Members outlined their positions as follows:

	UN accredited	Part of Government delegation
NPS Italia	No	No
Finland	Unknown	Unknown
Poland	Yes	Don't know
UK	Yes	Don't know
Denmark	Yes	Yes
Norway	Yes	Yes
Switzerland	Unknown	Unknown
Sweden	No (couldn't afford it at time of meeting ... but turned up anyway)	Not received formal invitation

It was accepted as important to keep clear that this was a meeting of UN member states, as in governments, to review where they are against the 2001 UNGASS declaration of commitment.

The UN had put much more effort into involving civil society and plwha to contribute to negotiations and meetings in New York. Some restriction on NGO participation was likely during the governmental meetings.

For those attending, it was seen as important to promote the work of HIV Europe in particular with potential new member organisation. Alongside this would be opportunity to have dialogue with other civil society organisations and other government delegations (including the EU).

The main reason for participation by civil society was to influence government delegations from within and, through them, the UN General Assembly high level meeting.

Per and Wojciech to circulate any documents received to all other members.

9 UNAIDS Programme Coordinating Board

Andreas drew attention to this call for delegates to take up a vacancy for the Europe region. The previous representative had been Svetlana from Ukraine. It was stressed that anyone applying should keep in touch with others as a voice for Europe was agreed as very important. It was agreed that the more people that applied the better, also that whoever was appointed, their performance would be monitored by HIV Europe.

10 International AIDS Conference, Toronto

Member participation was reported as follows:

Sweden	Unsure if funds available
Switzerland	Caroline and two others attending from AIDS Hilfe Switzerland
Norway	Sending 4 delegates
Finland	No funds, awaiting one scholarship
Italy	Sending 5 delegates, pharma funded
Denmark	Sending 2 delegates from HIV Denmark
UK	Sending 7 delegates from UKC, plus 3 from Ensuring Positive Futures programme; mix of funding
Poland	Sending 2 invited by pharmaceutical industry, await news on scholarships

It was agreed to try to hold some kind of informational meeting about HIV Europe in Toronto. The PWA Lounge would give an opportunity for a small meeting or networking, if we needed a larger meeting we would need to identify space.

Need to produce an information sheet about HIV Europe, circulate it so that everyone has it, can carry it and give it to anyone interested that they come across. Refer people to the website provided that there are some basic pages finished.

It was agreed as unfair to try to hold a formal meeting of HIV Europe at Toronto as not all members would be attending.

11 United States of America – travel ban on plwha

Members were reminded that anyone who transits via the United States of America in order to get to Canada will need an American visa – the US immigration ban on people with HIV could cause difficulties. There is a cumbersome process to apply for a visa. Per explained the difficulties experienced by a member of HIV Norway who applied for a waiver of ineligibility to enter the USA and [eventually] got it. The visa waiver is now glued in his passport, has a much shorter time limit than a normal visa, and shows a code that can be interpreted using Google to show that the person is an undesirable alien.

On the issue of travel, most countries have no travel restrictions against people with HIV for tourism or short stays. It was agreed that HIV Europe opposed the imposition of travel restrictions on plwha and that we should send a letter of protest to the US State Department, bearing in mind there are other countries that also impose a ban, and consider any action we can take through the European Union.

12 EU Civil Society Forum

Wojciech explained the history of the Civil Society Forum set up by the EU DG Sanco. Observers are not funded for participation, only accredited organisations. The next meeting would be 7/8 November 2006 and there was some existing concern over who chose the existing organisations and how representative they were, either of civil society or of plwha.

It was agreed to make efforts to get HIV Europe accredited for membership of the Civil Society Forum and the Think Tank. Andreas, who represents NORDPOL and Swedish RFHP, advised there was limited potential for new members unless they are very large or represent large networks.

A report of the 2nd meeting of the Think Tank was circulated. Andreas to email the power point presentations on a human rights questionnaire that had been prepared by AIDS Action Europe and EATG.

Wojciech added that he is a member of both the Civil Society Forum and the Think Tank due to his organisation's participation in the Integration

Project through AIDS Action Europe. Ton Coenen of AAE had proposed the civil society representatives should have equal footing at the Think Tank.

The meeting heard that issues on the agenda appeared to so far have been patient driven. The Think Tank is an official EU mechanism, whereas the Civil Society Forum is informal. There was concern that there were very few PWA representatives of the 28 members of the Civil Society Forum. There was a noted pattern where plwha are left off the agenda in favour of the largest AIDS Service Organisations.

Some members had used the human rights paper as the basis for further discussion in country, yet in Finland it was unclear who had filled it in and if there was anyone who actually had enough information to do so. It was suggested that maybe the Think Tank would have to suggest to the EU to put up the money to investigate the human rights issues properly.

It was agreed to keep monitoring the agenda and issues of both the Civil Society Forum and the EU Think Tank, in particular to pick up issues which are being raised by others. It was agreed to try to get a seat on the Civil Society Forum in 2007.

13 AIDS Action Europe

Whilst Denmark, Norway and Poland were already members of AIDS Action Europe, other members were not. This was discussed as despite the original scepticism over AAE, they do appear to be slowly representing some of the issues important to plwha.

It was agreed that member organisations should be encouraged to become members of AIDS Action Europe and that together we should ensure that our views and issues are listened to.

14 Future meetings

Frequency

After discussion it was agreed that there was a need to keep up a momentum and to physically meet twice per year. On that basis the next opportunity for a full meeting appeared to be late 2006. In between, the steering committee could meet if possible, or conduct business electronically (the website might help).

Next meeting

Wojciech extended an invitation to have the next meeting in Warsaw and reported his initial discussions with GSK Poland. Members were asked to check their availability for-

Warsaw 28/29 October 2006

Rome 20/21 October 2006 as the Italian Congress would be held in Rome at this time and it would give an opportunity to address the Italian National Congress of plwha about HIV Europe

It was agreed that two representatives per member organisation should attend, and that preparations should take account of potential new member participation (allow for six additional people).

Issues for next meeting

The following issues to be part of the agenda for the next meeting

- EU Civil Society Forum
- UNGASS feedback
- Toronto feedback
- Travel restrictions on plwha (some research needed here and perhaps a petition be prepared to present to the EU)

15 Evaluation of Rome Meeting

NPS Italia were thanked for the wonderful hosting arrangements, the marvellous weather, and particular thanks were given to Marcella for all her hard work with the logistics.

The issue of booking flights in country rather than by the host agency was discussed as it may be easier and cheaper for individuals to make their own arrangements and then produce receipts for reimbursement on arrival at the meeting. It was agreed that the cheapest economy class tickets should be booked.

In conclusion, Rosaria Iardino thanked everyone for attending and stated that NPS Italia were so glad that people had come to Rome for the meeting.