



REPORT FORM for SEMINARS

Title of event	Treatment update seminar – Prague 2006
Dates	24-26 November 2006
Place	Prague
Organizers	EATG
Report produced by	Tamás Bereczky

Aims and objectives

The Silent Epidemic –Treatment Issues in HIV/AIDS in the Central East European Region

While the HIV/AIDS epidemic has become “established” in the western parts of Europe, we can register a new wave of infections in the eastern and central regions. The free flow of people over the borders and the exchange of cultures have also brought about a new threat of more and more people getting infected with HIV in the new accession countries and the candidate states. Essential structures, NGOs and treatment experience are absent or at best fragmented in these regions of Europe. The seminar organized by EATG in Prague aimed at spreading treatment experience and awareness to NGOs, activists and PLWHA in the countries of the CEE region. In some of the countries, HIV/AIDS NGOs are non-existent or on the verge of becoming dysfunctional for the lack of funding and initiative. In the framework of an intensive three-day exchange of views and know-how we tried to give new impetus to the work of patient organizations and treatment activists in the region. At the same time, we also wanted to learn more about the situation, difficulties, issues and questions regarding treatment and HIV/AIDS in the CEE area, so that this essential information can be channeled back to the European Union and its decision makers.

Participants

The seminar was aimed at people living with HIV/AIDS and treatment activists in Central and East Europe with particular focus on Central European states, accession and candidate states of the European Union. Altogether 24 participants attended from the following countries:

Czech Republic
Estonia
Hungary
Latvia
Lithuania
Poland
Romania
Slovakia
Albania

Most of the participants were themselves persons living with HIV. They came from various backgrounds: we aimed for participants who are involved or are starting their work in treatment activism. We asked about their treatment activism and involvement in the application forms, and this was one of the criteria for eligibility to participate. Doctors or health care professionals were not allowed to attend. In order to improve the fluency of the training, we limited the participation to English speakers only, and no translation was provided, which meant increased interactivity and better flow of information with the trainers. We also wanted to make sure that the integrity of the training remains intact. All of them were representing interest or patient organisations for PLWHA. MSM and IDU communities were equally represented. Some participants represented special organisations for women living with HIV.

Trainers/experts

The training was delivered by the following trainers:

Konov, Svilen – EATG

Svilen has a degree from the London School of Hygiene and Tropical Medicine, and has a broad knowledge on clinical trials design and methodology. In addition he works for HIV i-Base in London as a treatment consultant for people living with HIV/AIDS. His special interests are in pharmacogenomics and mathematical modelling.

Dr. Dr. Dressler, Stephan – EATG

Stephan comes from Berlin, Germany and has a background as physician and philosopher. He served as assistant in the department of information on AIDS at the Federal Health Office of Germany. He is a co-founder of EATG, and provides seminars on all aspects of HIV/AIDS, hepatitis and STI's in co-operation with national NGO's. Stephan has served investigators, the European Community Advisory Board (ECAB) and pharmaceutical companies as a consultant in the design of clinical trials of antiretroviral therapies and opportunistic infections.

Guarnieri, Mauro – EATG

Mauro has been an AIDS activist since 1996. He joined the Open Society Institute Europe in 2006 as programme officer, IHRD. A member and former chair of EATG and ECAB and the Italian Community Advisory Board, his leadership has extended to boards of many bodies including the editorial board of EATN, the International Treatment Preparedness Coalition and a number of other organisations. Mauro is an experienced trainer and consultant for PLWHA in Eastern Europe and Central Asia with special focus on IDU.

Mayer, Vlastimil – EATG

Vlastimil is a medical doctor and a virologist. He was the head of the National Reference Laboratory for AIDS of Slovakia between 1984 and 2004. Vlastimil works as a university lecturer and co-ordinator for preventive programmes against HIV. He is the founder and chair of the League against AIDS of Slovakia. Member of EATG, steering committee member of ECAB.

Malesevic, Smiljka – EATG

Smiljka is Serbian, living and working in Belgrade with an NGO dealing with sexual and reproductive health and rights. She has been internationally and voluntarily involved in HIV treatment activism. Smiljka has been a member of EATG since 2001 and a member of its board of directors since 2005. She is mainly engaged in treatment access and literacy especially in Eastern Europe and the Balkans.

Bereczky, Tamás – EATG

Tamás is a trained teacher and trainer, community advisor and treatment activist for PLWHA. A member of EATG and steering committee member of ECAB, he has been working extensively on access and treatment literacy issues for PLWHA in Central and East Europe. Member of

several Hungarian NGO's and founder of hivpozitiv.hu, Tamás is currently working on a comprehensive training programme for medical professionals on HIV/AIDS, opportunistic infections and co-infections.

Mahaut, Laurent – EATG

French born Laurent is currently working in the offices of EATG in Brussels as training and logistics co-ordinator. He has extensive experience with organising various events, conferences and meetings both in Belgium and internationally.

Program

The program concerned the following key topics:

Immunology, virology and HIV basics

Introduction to ARV

Side effects

Adherence

Treatment and access in CEE

IV drug use and ARV

Pregnancy and women's issues

Opportunistic infections and major co-infections

Hepatitis

Case studies and interactive sessions to complement the lectures and to deepen the knowledge and experience of participants.

There were no substantial changes in the planned program.

Methodology and training manuals used

This event was planned and designed as a more informal training session. The available time was divided between presentations and interactive exercises based on case studies focusing on various knowledge fields.

The materials used for preparing and conducting the training were mainly based on the STEP Manual developed for EATG by HIV i-Base. The manual and all related training materials including slides and case studies can be downloaded from the seminar website:

www.pragueseminar2006.blogspot.com.

The slides and case studies were complemented by the personal knowledge and experience of the trainers. All presentation materials and case studies were also discussed in detail by the group of trainers. Interactive approach by the participants was encouraged through different plenary and group exercises. This interactive design was very well received by the participants, and our general impression from the evaluation of the seminar was that an even more intensive focus on participant involvement and interactive exchange of concepts and ideas would have been advisable. This experience will be used in the design of future training courses.

Successes

The wide geographical outreach of the seminar can be seen as a clear success. We received very many applications also from Central Asia and more distant parts of East Europe, which lets us conclude that it would be absolutely necessary to organise similar events in those geographical regions as well.

We understand from the evaluation sheets returned by the participants that the information conveyed was well received and digested, and it was visibly very much needed and requested by the participants.

The venue and the organisation were apt and successful. We could work in a comfortable and reliable environment, which contributed to the general success of the event.

There was a major interest shown by the participants to join EATG which allows us to conclude that we could portray a good image of the organisation, and thereby convince the participants that international treatment advocacy and training is indeed working.

Limitations

The most important limitation was that no printed training materials were available. This was partly due to budget constraints, and partly to the fact that there have been poor results with previous hardcopy materials in other international training sessions. Expensive and bulky printouts are usually discarded after the training course is completed. This aspect of future trainings needs better planning and innovative input.

Recommendations for the future

We found that it would be very advisable to expand the list of eligible countries for the training. The eligibility criteria seem to be unreasonably strict, and sometimes also create an unjustifiable separation of integrated regions.

Despite the initial difficulties and objections we found that using one language for the training proved very useful, and eased communication. Most of the information about this field is available in English, and the "universal" language of communication among advocates seems more and more to be English. Using English only allowed the participants also to work more interactively, and to learn more about how international networking is done.

We recommend to develop a general pool of case studies for the individual training modules. This allows trainees to apply the information provided more to their everyday situations.

We recommend an innovative exercise for the updating and standardisation of training materials for EATG and the Integration Projects.

General syndication and free access to standardised materials on HIV/AIDS treatment literacy would be very advisable.

It would also be quite adequate to compile a registry of available trainers for future projects. We are convinced that the use of such a joint pool of skills and knowledge could greatly contribute to the success of future events.

Appendices:

Actual agenda - attached

Presentations and additional information – please download from www.pragueseminar2006.blogspot.com

Evaluation form and its summary – attached