

## Southern States Treatment Activists Seminar Barcelona; 12-13 December, 2003

### **Preliminary program**

Seminar moderators: Kiros Kokkas, Ferran Pujol

Seminar Trainers: Kiros, Ferran, Wim, Simone

Seminar tutors: Mauro Guarinieri, Pedro Marques, Nikos Dedes, Michael Meulbroek, Lital Hollander

### Friday afternoon

14:30 – 15:30 – Introduction

14:30 – 14:45 – Welcome - Mauro Guarinieri

14:45 – 15:10 – Aims and objectives of the 5<sup>th</sup> SSC conference – Lital Hollander

15:10 – 15:30 – The program at a glance – Ferran Pujol / Kiros Kokkas

15:30 – 16:00 – The agenda of the activist – Mauro Guarinieri

16:00 – 16:45 – Basic Science – Maite Suarez

16:45 – 17:15 – coffee break

17:15 – 18:00 – Managing treatment – Maxime Journiac

18:00 – 19:00 – round table – transforming knowledge into strategies – Mauro, Maite, Maxime

### Saturday morning

09:30 – 09:50 – Greek activists vs. health ministry – a case study – Nikos Dedes

09:50 – 10:20 – Advocacy and activism – Kevin Moody

10:20 – 10:50 – Regulatory issues and pricing – Emanuel Trénado

10:50 – 11:20 – Coffee break

11:20 – 12:50 – National Focus Groups “advocating for better prices vs. the risk of delaying registration”

Moderators: Pedro, Mauro, Michael, Nikos

12:50 – 13:30 – Presentation and discussion of group results – Group moderators and speakers

### **13:30 – 15:00 – Lunch Break**

### Saturday afternoon

15:00 – 15:20 – campaigning for liver transplant in HIV+ patients in Spain – Michael Meulbroek

15:20 – 15:50 – HIV co-infections – Simone Marcotullio

15:50 – 16:20 – long term side effects and quality of life – HeideMarie Kremer

16:20 – 16:50 – Coffee break

16:50 – 18:20 – Transnational working groups – build a communication plan on cardiovascular risk on HIV+ patients on HAART

Moderators: Maite, Lital, Kevin, Maxime

18:20 – 19:00 – presentation of results and discussion - Speakers and moderators

## Sunday morning

09:30 – 10:00 – From patient advocacy in southern Europe to community representation in UNAIDS – Pedro Marques

10:00 – 10:30 – working with underprivileged groups – Stefan Wiessner

10:30 – 11:00 – Principles and benefits of networking – Filippo von schloesser

11:00 – 11:30 Coffee break

11:30 – 13:00 – National working groups – create a model for a local network of treatment activists, and its relationship with the EATG

Moderators: Kiros, Ferran, Wim, Simone

13:00 – 14:00 Closing plenary - Stipulation and signing of contract Southern Activists vs. EATG – seminar trainers and moderators, chair of the EATG

**14:00 – 15:00 – Lunch**

**15:00 – Leaving for buses, trains, airports**

Southern States Treatment Activists Seminar  
Barcelona; 12-13 December, 2003

**Program Concept**

Proposed moderators: Kiros Kokkas, Ferran Pujol

Seminar Trainers: Kiros, Ferran, Wim, Simone

Seminar tutors: Mauro Guarinieri, Pedro Marques, Nikos Dedes, Michael Meulbroek, Lital Hollander

**General Issues (to be kept in mind by all trainers/tutors/speakers):**

- Application of international experience in local reality
- Information: how to find / validate and how to establish what is relevant
- Added value of EATG
- Transmit feeling of international community
- Receiving follow up / giving feedback
- Meet other TAs / know other CABs
- The experience of the existing CABs

**Friday afternoon:**

**Introduction to the seminar:**

Mauro – EATG chair

Lital – aims and objectives of the program, contract with participants

Ferran/Kiros - the program at a glance

**First session – Why a treatment expert**

Tutor: Mauro

Opening: the agenda of the activist – from personal intervention to the constitution of a CAB - Mauro

(aim of talk: show that activists are not scientists, they are ordinary people equipped by a series of skills that can be acquired one by one)

Learning session 1: Basic Science

Message: you do not need to be a Scientist in order to be a good treatment activist

Skill: work with pharmas

Proposed speaker: Maite Suarez

Learning session 2: Managing treatment

Skill: strategy planning

Proposed speaker: Maxime Journiac

Closing session:

Round table – how to tie knowledge to strategy

Tutor and the two speakers

**Saturday Morning**

**Second session – Why a Treatment Activist**

Tutor: Nikos

Opening : a “case study” – the Greek activist vs. Ministry – growing up in ECAB to influence local situations - Nikos

(skill – working with the authorities)

Learning session 1: Advocacy and Activism

Proposed speaker: Kevin Moody

Learning session 2: Regulatory issues and pricing

Proposed speaker: Emanuel Trénado

Working session:

National Focus groups .

The dilemma of advocating for better prices vs. the risk of delaying registration

Moderators: Seminar tutors (i.e. Pedro, Mauro, Michael, Nikos). Seminar trainers may be presents as consultants to the group.

Each group elects a representative to present the focus results to the plenary

Aims of working session: clarify and elaborate the “risks” of activism

Closing:

Groups’ results

Representatives discuss with the session tutor and two speakers on solutions to the problem and the potential benefit of interacting with the EATG.

**Saturday Afternoon**

**Third session – How a Treatment Activist**

Tutor: Michael

Opening: the campaign for liver transplant for HIV+ individuals–Michael  
(aim of talk: demonstrate how the subjective involvement of the community can be harnessed and turned into a potent communicative tool)

Learning session 1: HIV co-infections

Proposed speaker: Simone Marcotullio

Learning session 2: long term side effects and quality of life

Proposed speaker: HeideMarie Kramer

Working session: TransNational groups:

Working issue – build a communication plan for the following item:

“in HIV+ individuals >40 years on HAART, the cardiovascular risk increases by 20%”

Communication plan:

1. Message for a TA appearing in TV
2. Informative communication on the NgO website
3. Backbone for an article in a newsletter
4. Awareness campaign addressed at HIV clinicians

Objective of the plan: Obtain the reimbursement of lipid lowering drugs and reduce cigarette smoking, WITHOUT creating fear that will motivate abandonment of therapy

Proposed moderators: Maite, Lital, Kevin, Maxime

Aim of the session: using communications skills, choosing the right tools and specific language for each target

Closing:

Plenary: presentation of results and discussion

Short learning session: the rules of communication

Proposed speaker: Lital

**Sunday morning**

**Fourth session – Group work for Treatment Activism**

Tutor: Pedro

Opening : From patient advocacy in a small Southern European country to community representation in UNAIDS – Pedro  
(talk should be practical, tangible, demonstrate the role of international collaboration (i.e. EATG) in growth of skills and visibility of populations)

Learning session 1: working with underprivileged groups (i.e. inmate, immigrants)

Proposed speaker: Peter Weissner

Learning session 2: Principles and benefits of networking

Proposed speaker: Filippo von Schloesser

Working session: National groups:

Working issue – construct a collaboration / follow up contract between the local group and the EATG –

Commitment offered by the local community

Support requested from EATG

Follow up expected from EATG

Proposed moderators: the trainers – Kiros, Ferran, Wim, Simone

Aim of the session: create a network model taking into account the different figures of interaction (see below)

Closing:

Plenary: Lital presents the contract stipulated on the basis of the four groups' results.

Invites for signing in names of the states:

Pedro – Portugal, ex UNAIDS representative

Filippo – Italy, ex EATG chair

Joan – Spain, ex community chair of IAC

Nikos – Greece, EATG Bod and community liaison for Glasgow

Signs on behalf of the EATG – the Chair - Mauro

