



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, NGO’s 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 NGO’s, activists and PLWHA in the countries of the CEE region. In some of the countries HIV/AIDS NGO’s 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. 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's

Side effects

Adherence

Treatment and access in CEE

IV drug use and ARV's

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

Summary of results from the evaluation form.

List of participants/NGOs that were represented.

Small selection of the presentations made.

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

Date, time	What?	Details	Who?
23.11. Thu.			
Afternoon	Arrivals		
2000 – 2200	Dinner		
24.11. Fri.			
1000 – 1130	Plenary Session	Introduction Introduction of participants Pre-evaluation test HIV Basics	Tamás Participants Evaluator Vlastimil
1130 – 1145	Coffee break		
1145 – 1315	Plenary Session	Introduction to ARV's Side Effects Adherence Adherence case study	Stephan Svilen Svilen Svilen
1330 – 1500	Lunch		
1500 – 1545	Interactive session	Treatment and access in CEE[m1] Presentation + discussion and forum of ideas and experiences	Tamás Participants
1545 – 1555	Coffee break		
1600 – 1700	Interactive session	Participants present their issues and needs and countries	Participants Smiljka
1700 – 1715	Coffee break		
1715 – 1800	Plenary session	Drug use and ARV's Case study – Drug use and HIV	Mauro Mauro
2000 – 2200	Dinner		
25.11. Sat.			
1000 – 1045	Plenary	Pregnancy and women's issues	Svilen
1045 – 1130	Plenary	OI's and TB	Stephan
1130 – 1145	Coffee Break		
1145 – 1215	Plenary	Explain how case studies are worked	Tamás
1215 – 1315	Sections	Working on case studies: Quality of life Sex workers (male, female) Social stigmatisation Travelling HIV+[m2]	Participants
1330 – 1500	Lunch		
1500 – 1530	Plenary	Feedback from speaker of each workgroup	
1530 – 1615	Plenary	Hepatitis A, B, C	Stephan Mauro
1615 – 2000	Free time		
2000 – 2200	Dinner		
26.11. Sun.			
1000 – 1200	Plenary and summary	Follow up for participants, future trainings, post evaluation test, etc. Summary Input from participants Introduction of deliverables/materials	All trainers + Evaluator
1200 – evening	Departures		

Prague Seminar, analysis of Evaluation Forms

General Impression

	Urgency of the Seminar Topic	Scope, coverage of content and preparation	Relevance to practice, chance to implement	Presentation form of content	Performance of presenters and facilitators	Seminar Logistics in General	Fulfillment of your expectations	Your general impression of this seminar
TOTAL "Very Satisfying" - A	13	13	11	10	14	15	11	15
B	7	5	7	6	5	5	9	6
C	2	3	4	5	3	2	1	1
D	0	1	0	1	0	0	1	0
E	0	0	0	0	0	0	0	0
Not Satisfying at all - F	0	0	0	0	0	0	0	0
1	a	a	a	a	a	a	a	a
2	b	b	b	a	c	b	b	b
3	a	a	a	a	a	a	b	a
4	a	a	a	a	a	a	a	a
5	a	a	a	a	a	a	a	a
6	a	a	b	b	b	c	b	b
7	b	a	b	a	a	b	a	b
8	b	c	b	c	c	b	c	c
9	a	b	a	a	c	a	a	a
10	b	c	c	c	c	b	b	b
11	a	c	a	b	a	b	b	a
12	a	a	a	b	a	a	a	a
13	a	a	a	a	a	b	a	a
14	b	a	b	a	a	a	b	b
15	c	b	b	c	a	a	d	b
16	a	b	b	b	a	a	d	b
17	c	d	c	c	b	a	a	a
18	a	a	b	a	a	a	a	a
19	b	b	a	b	a	a	b	a
20	a	a	a	a	a	a	a	a
21	b	a	b	d	b	a	a	a
22	a	a	a	d	b	a	d	a

Sessions

Which sessions of the seminar were the most useful to you?	HIV Basics	Introduction to ARV's	Side Effects	Adherence	Treatment and Access in CEE	Drug Use and ARV's	Pregnancy and Women's Issues	OI and TB	Case Studies	Hepatitis
TOTAL	10	11	12	9	10	8	9	11	9	11
1	x		x		x			x		
2	x	x	x	x	x	x	x	x	x	x
3	x	x	x	x	x	x	x	x	x	x
4							x			
5	x	x	x	x	x	x	x	x	x	x
6										
7			x	x		x				
8			x							
9			x					x	x	x
10	x									
11	x		x	x					x	x
12	x	x	x	x	x	x	x	x	x	x
13		x			x					
14										
15	x									
16	x	x	x	x	x	x	x	x	x	x
17										
18					x				x	
19	x	x	x	x	x	x	x	x	x	x
20		x								
21	x	x	x	x	x	x	x	x	x	x
22		x	x			x	x	x		x

LIST of PARTICIPANTS

Note: we did not include the names of the participants as several are People Living with HIV/AIDS who risk to face severe problems if their HIV status (or even their personal involvement in HIV/AIDS advocacy) was to be revealed accidentally.

	EATG Members	Country	Organisation	
1	Mayer, Vlastimil	Slovakia	EATG	trainer
2	Bereczky, Tamas	Hungary	EATG	trainer
3	Malesevic, Smiljka	Serbia	EATG	trainer
4	Guarnieri, Mauro	Serbia	EATG	trainer
5	Dressler, Stephan	Germany	EATG	trainer
6	Mahaut, Laurent	Belgium	EATG	staff
7	Konov, Svilen	UK	EATG	trainer
	Participants (local)			
1		Czech R	Credum	
2		Czech R	Credum	
3		Czech R	Credum	
	Participants (abroad)			
1		Romania	UNOPA	
2		Romania	ARAS	
3		Hungary	Pozitivan Gondolkodo Barati Kore	
4		Estonia	Life is Going On	
5		Romania	Romanian Angel Appeal	
6		Romania	Sens Pozitiv	
7		Albania	PLWHA Association	
8		Latvia	Agihās	
9		Hungary	Anonimous AIDS Association	
10		Latvia	DIA+LOGS	
11		Estonia	Estonian Network of PLWHA	
12		Slovakia	Odysseus	
13		Albania	Confidential Counseling Center	
14		Poland	Net Plus	
15		Bulgaria	Hope Sofia	didn't come
16		Lithuania	Lithuanian Positive Group	
17		Estonia	Estonian Network of PLWHA	
18		Lithuania	Positive Life	
19		Hungary	Pluss HIV	
20		Romania	UNOPA	
21		Romania	UNOPA	
22		Lithuania	I Can Live	
23		Lithuania	Association of HIV Affected Women and their Intimates	

Access to Treatment in Central East Europe *Issues and Challenges*

tamas@eatg.org



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The Silent Epidemic



- Central-East Europe is the new front of the HIV epidemic
- Issues similar due to historical and cultural reasons
- Number of new infections increasing rapidly
- New face of the disease – no longer a gay problem
 - Women
 - Young individuals
 - Sex workers
 - IV drug users
 - Migrant communities (Roma and guest workers)
 - Prison population
 - Heterosexual infections on the rise – exotic holidays

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Access to Testing



- Poor access to HIV tests everywhere in the region
- Underreporting of infection rates
- Epidemiological issues
 - Late testing = late diagnosis = early death from AIDS
 - Late testing = people keep infecting
- Diagnostic preparedness of doctors missing or erratic
- Co-infection (HBV, HCV, TB, Syphilis)
- Stigma and social exclusion

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How is it in your country?



- What is the typical profile of PLWHA?
- Any information about prison population?
- How can you access new patients?
 - Internet?
 - Phone hotline?
 - Personal counselling?
- Social stigma?

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Improving Testing



- Early detection and diagnosis are paramount
- More HIV/AIDS centres needed throughout the region
- Sentinel testing and surveillance needed
- More education and information to doctors
- Availability of quick tests
- Enforcement of EU standards
- Co-operation with suppliers of diagnostics
- Improve awareness
- Disseminate information
- Combat stigma and socio-psychological issues

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Changing Prevention



- Prevention must be adjusted to the current nature of the epidemic:
 - Gay and MSM individuals already covered well
 - Vulnerable populations must be targeted
 - Women and sex workers
 - IV drug users a particular issue
 - Information about treatment – treatment preparedness
 - Changing paradigm of thinking and attitude towards HIV

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How is it in your country?



- Is there any information available on safe sex?
- Positive prevention
- Is there information to promote treatment preparedness?
 - Manual
 - Internet
- What can be done to combat social stigmatisation and exclusion?
 - Case studies
 - Best practice

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Access to Treatment



- Common problems of new accession countries
 - Standards not always and completely applied – a rare/neglected disease area
 - EMEA labelling requirements difficult to enforce, small populations, reluctant drug manufacturers
 - Registration status of drugs often unclear and confusing
 - Foreign aid often no longer available or difficult to access
 - Organisations of PLWHA weak or ineffective (stigma, resignation, lack of knowledge about NGO work)
 - Health systems lack money, experience and know-how
 - Pricing problems with pharma companies after EU accession

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Access to Treatment



- General, common problems of countries not within the EU
 - Standards even less consequently applied
 - Vulnerable populations present a particular problem (prisons, Roma, IV drug users)
 - Lack of information and awareness
 - Difficult access to complementary medical care: surgery, dentist etc.
 - Funds for ARV a field of corruption, lack of transparency

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IV Drug Use and Substitution



- Governments reluctant in all countries
 - „IDU's are not reliable”
 - „Too much hassle and work”
- Substitution is key for successful ARV therapy
- Choice of substitution drugs
 - Methadone
 - Buprenorphine (Subutex)
- Special centres needed for special requirements
 - Psycho-social support
 - Needle exchange
 - Educational materials etc.
- Role of patient organisations

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General Issues – Drugs



- Not all drugs are registered
- Health insurance issues – who pays for the drugs?
- Treatment is usually free of charge
- No paediatric formulations, Romania
- High prices of ARV's
- Overly centralised systems
- Trials not performed in the area – situation similar to the southern states in the 1990's (trials are performed now, but in a context of weak ethics)
- Role of patient organisations like EATG

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How is it in your country?



- Are all drugs registered?
- Do you have to pay for the drugs?
- Are there any clinical trials going on?
 - And do you know anything about them?
- Are patients organisations involved in trials?
 - And should they be?
 - How?

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General Issues – Social Field

- Lack of information and awareness
- Stigma and social exclusion
- Very little psycho-social support
- Inefficient patient organisations
- Patients not involved in decision taking
- Patients' rights

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General Issues – Care

- No reliable standard of care
- No or erratic general medical care for PLWHA
- High cost and unreliable system for the care of OI's and co-infection
- Lack of reliable funding
- Lack of co-operation or exchange of information among countries
- Missing options for second-line & salvage regimens

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Solution

Reach out – Learn – Co-operate – Network

PATIENT ORGANISATIONS ADVOCACY WORK

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Credits

- I owe thanks for their valuable help to:
 - Ana Balkandjieva, Bulgaria
 - Dr. Dénes Bánhegyi, Hungary
 - Gus Cairns, UK
 - Dr. Stephan Dressler, Germany
 - David Haerry, Switzerland
 - Smiljka Malesevic, Serbia
 - Dr. Vlastimil Mayer, Slovakia
 - Daniel Novichkov, Russia
 - Lucia-Maria Stirbu, Romania
 - The EATG staff

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LESSONS LEARNT

Day 1



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Immunology and Virology



- For monitoring HIV infection we use two essential tests:
 - CD4 count / CD4 percentage – shows the condition of the immune system and warns us of the possibility of OI's – when to start?
 - Viral load test – shows the amount of free virus in the blood – does the treatment work?
- One test doesn't say anything – it is the trend that counts.

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ARV's



- Around every virus there is a human person.
- The goal of each treatment is to stop the virus from reproducing, so that the immune system can recover.
- Each treatment needs to be a combination of at least three drugs, so that the virus has less chance to escape.

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ARV's – when to start?



- The decision is individual, taking into consideration personal situation – a person should start when he/she feels ready for it – there is always some time to think
- Most international guidelines recommend to start
 - when there is an AIDS defining illness
 - when CD4 drops below 200 (below 350 needs close monitoring)

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Side Effects



- No drug is perfect – there are always side effects
- In the most cases side effects are mild to moderate, and disappear after 4-6 weeks
- Any change or problem should be reported to the doctor – don't ignore side effects!

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Adherence



- Adherence is taking the drugs exactly as prescribed: exact number of pills right on time with all dietary requirements and being aware of possible drug interactions with other medications.
- The purpose of adherence is to always have enough drug in the body to prevent the replication of the virus.
- The more you are adherent, the longer the combination works.

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ARV's and Drug Use



- ARV's interact with illicit drugs and substitution treatment (methadone, buprenorphine) – it is important to adjust the doses.
- Adherence is increased when on substitution treatment.
- Harm reduction works!

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Treatment Preparedness



- The one who knows is the one who asks questions – knowledge is power.
- If you know what to ask for, you get what you want – fight for your rights.
- Educate yourselves, get organised, start demanding.

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LESSONS LEARNT

Day 2



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Pregnancy and HIV



- You can have a child if you are HIV+ (man or woman).
- The woman should be on a combination therapy that works – low viral load is paramount.
- Certain drugs and procedures should be avoided.
- Choose natural birth rather than C-section.
- Contact EATG for links to CREAThE.

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Opportunistic Infections and TB



- While OI's are less common, they can still occur when CD4 is low.
- There are various types of OI's: viral, bacterial, fungal and protozoal.
- OI's can be cured or suppressed but are often difficult to treat.
- A working immune system is the best protection against OI's → HAART.
- TB requires a lengthy and strict treatment – follow it through for success.

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Hepatitis A, B, D, G



- Inflammation of the liver – different viruses, similar problems, different treatments.
- Transmission mostly through blood but also through body fluids.
- Vaccination is available and recommended.

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Hepatitis C



- Liver failure becoming the leading cause of death for HIV+ people where ARV treatment is available.
- Treatment are limited but research is ongoing.
- It is possible to have concurrent treatment of HIV and HCV.
- Problems with access to treatment for IDU.

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Contacts and Materials



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Materials of this seminar



- Download the presentations and manual in English and Russian from:
www.pragueseminar2006.blogspot.com or
www.eatg.org
- Use the e-mail list to contact each other and the trainers.

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STEP Manual



- Translations are under way into
 - Hungarian
 - Slovakian
 - Czech
 - Polish
 - Romanian
- Available for download by early next year.
- Russian already available with I-Base and EATG.
- Enquire with EATG.

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Becoming a member of the EATG



- Check our website on www.eatg.org
- Write mail to tamas@eatg.org
- You will be informed of the process.

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