

# Patients and doctors together against HIV/AIDS



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# Numbers of PLWHA in South East Europe

**2006: 23,854**

## **Countries with high rates**

Romania 11 035

Greece 7 371

Turkey 1 922

Serbia & Montenegro 1 290

## **Countries with low rates**

Kosovo 37

FYR Macedonia 76

Bosnia & Herzegovina 107

Albania 148

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Bucharest, Romania. February 2006

# Access to treatment and care:

- PLHIV who require treatment have variable access to it
- Treatment is available free of charge for all patients in need in most countries
- Care is of the international standards, but patients have difficult access to their medical records
- Often problems occur with financing and pricing of ART
- In some countries drugs are funded by the GFATM
- Problems caused by stigma and discrimination are common
- Serious problems exist for access to care for non-HIV health problems

# Access to treatment and care:

- PLWHA must usually pay for treatment of opportunistic infections (OI's)
- Poor management of the funds/budget for ARV and OI's
- High drug prices due to taxes and use of distributors
- Low AIDS healthcare budget that does not cover all the eligible patients
- Slow registration of new drugs leads to many patients having unnecessary toxicity, multiple resistance, or therapeutic failure
- The patient usually has little influence on the doctor's decision around treatment and care
- Treatment of HIV infection in infants and children is poor
- Lack of legislation for legal/illegal immigrants at the national/regional level

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# Access to treatment and care: further issues

- **Discontinuous Antiretroviral therapy**

which includes: interrupting treatment until the appropriate therapy became available as well as changing components of the combination of drugs that individual patients are prescribed

- The **doctors and nurses at the HIV Clinic** are a significant and often **only source** of support for PLHIV

- **Non-HIV related medical care** is variable

- **Weak adherence to the codes of medical confidentiality by healthcare personnel** who refuse medical treatment, directly or indirectly. Negative experiences contribute to patients feeling stigmatised and marginalised from 'normal functioning' society

- **Social consequences of HIV:** multi-layer discriminatory experience

- within health care settings
- in bureaucratic procedures
- in employment
- within a patients local community
- even amongst their close friends and family

- **Community participation in NGOs and self support** is limited

# Treatment advocacy

## Needs, obstacles and problems

PLHIV are generally informed about the process of getting HIV treatment  
Some PLHIV knows the essential list of ARV medicaments used in their country  
Discontinuous ARVT can be a problem  
Registration of ARV drugs in many countries  
Need for PLWHA to participate in their care and treatment decisions  
Confidentiality of HIV status in medical documents and medical communication  
Medical care other than ART as part of the comprehensive medical care  
High prices on ARVs, OIs and co-infection treatment in many countries

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# Treatment advocacy

## Needs, obstacles and problems

- Medical care other than ART as part of comprehensive medical care
- High prices on ARVT, OI and co-infection treatment in many countries
- High cost of treatment monitoring and limited access
- Human rights, legal issues, access and maintaining jobs, equality
- Quality of social services
- Treatment in prisons
- Education for medical staff
- Special law/laws for PLWHA or ensuring rights of PLWHA are covered by sectoral legislation
- Centralization of the treatment system is a problem
- Transparency and involving PLWHA in decision making process

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# Treatment issues

## Patients

- **Should believe in the benefit of treatment**
- **Try to reduce fear and control about side effects**
- **Develop a support network**
- **Build confidence in doctor and staff team**

## Doctors

- **Should see patients as partners in treatment**
- **Devote time for education and conversation with patients**
- **Be aware of patients lifestyle and their attitudes about treatment**
- **Treat without compulsion**
- **Find causes of patients hesitation about commencing treatment**

# Recommendations

Patients need to:

- **Begin the education process around HIV at home**
- **Try to define a relationship style with their doctors**
- **Prepare for appointments**
- **Communicate treatment requests in a spirit of mutual respect**
- **Be prepared for the emotional content of clinic visits**

Doctors need to:

- **Recognize that the uncertainties of the epidemic demand a flexible response**
- **Be prepared to describe all sides of the medical issues confronting patients**
- **Support patient interests in monitoring and treatment**
- **Support the patient's goal of survival and of good quality of life**
- **Fight for effective unapproved therapies to be available**

# Conclusions

- Education is the way forward
- Good interaction between doctors and patients is an important part of an effective strategy for the improvement quality of life for PLHIV
- Open communication, cooperation and active inclusion of PLHIV within their own care is desirable
- Numerous studies show there is a relationship between knowledge of PLHIV and experience of their doctors with better outcomes, including survival