

Prevention and control of viral hepatitis: Role and impact of liver patient groups in Europe

CROATIA

Croatian **A**ssociation of **T**reated and **I**ll with **H**epatitis

CATIH “HEPATOS”

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president

Lucca, 2008 March 13th

1) History of the organisation

- Founded in 2000
- Aims:
 - ✿ Prevention
 - ✿ Improvement of quality of hepatitis patients' life in Croatia
 - ✿ Increase of public awareness



2A) Objectives and role of the organisation

OBJECTIVES

- prevention of viral hepatitis
- improvement of status and quality of hepatitis patients' life
- reorganization of health care
- protection of reproductive health in children and youth
- help to hepatitis patients
- education of risk groups (children, youth, pregnant women, war veterans, drug addicts, prisoners...)
- raising awareness, destigmatization of viral hepatitis
- promotion of rights and interests of hepatitis patients
- promotion of civil society and volunteering

2B) Objectives and role of the organisation

Role of the organisation



2C) Objectives and role of the organisation

ROLE OF THE ORGANISATION (2)

- Hepatos was the first to publicly speak about hepatitis & continue to speak permanently
- Conducts a campaign aimed at raising awareness of wider community
- Our recognizability is very high:

Reporters often call the Hepatos seeking information and relevant institutions (professionals, Ministry of Health) consult us when they enact laws

3A) How is it organised?

- 3 full time plus 2 part time paid staff ; 24 volunteers / including specialists hepatologists /
- **ORGANIZATIONAL STRUCTURE:**
 - Assembly
 - Executive board
 - Supervisory board
 - Advisory board
- **Assembly** is the supreme steering body of the association consisted of all active members.

3B) How is it organised?

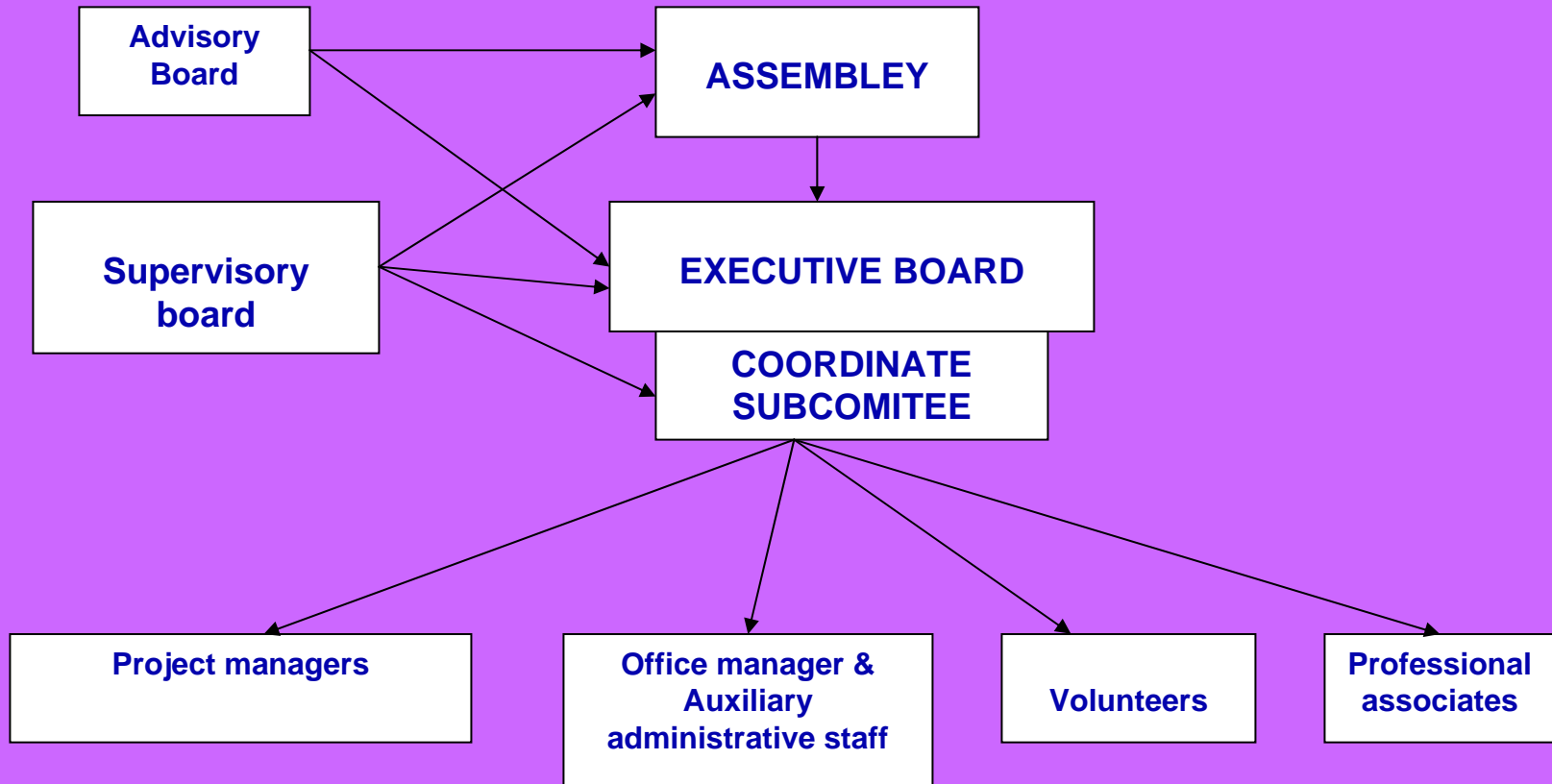
- **Executive board** is a steering body authorized to reach decisions between two Assembly meetings. Executive board is acting as a Steering committee but it's called Executive board because only 40% of its body is consisted of Association's employees on the executive level.
- Work of the Executive board is supervised by a Supervisory board and counseled by Advisory board.

3C) How is it organised?

Membership

- Regular members
- Supporting members
- Honorary members

3D) How is it organised?



4) Target audience

- **The target audience**
 - hepatitis patients and members of their families
 - children and youth
 - risk groups (drug addicts, war veterans, prisoners...)
- **HEPATOS is reached by its target audience**
 - media appearance, billboards
 - web page
 - distribution of informational-educational materials in health and educational institutions
- **Hepatos has more than 2000 beneficiaries**

Our users (beneficiaries) are citizens regardless on their sex, age, national religious any other affiliation. Our services are not conditioned by enrollment in our membership.

5A) Services and Activities: General

- Activities performed by the group:
 - Constantly informing of public through www.hepatos.hr
more than 500 appearances in media within 6 years
 - Distribution of informational-educational **materials** in health institutions, schools drug addict associations, public activities
 - Raising awareness by marking
WHAD 2004 - 2008

Marking WHAD



5B) Services and Activities: General

- Counseling center for hepatitis patients and members of their families – free informative, psychological and legal help and advice.
- Toll-free phone
- Public lectures and tribunes
- Lectures in schools
- Lectures for risk groups (drug addicts, war veterans, prisoners...)
- Advocating and lobbying
- Developing of health sub sector by founding branches and new associations even out Croatia

6) Services and Activities: Prevention

- This is the 4th consecutive year that we conduct educational lectures in final high school classes in our district along with distribution of informational-educational materials
- Distribution of brochures about hepatitis to all 6th grade elementary school students during the obligatory vaccination against HBV – more than 5,000 pupils per year

7) Support and Financing

- No membership fee
- No private donors
- Government grants/government contracts
- Foreign government support
- Pharmaceutical industry (Roche, Schering Plough, GSK, Novartis)
- Foundations grants— CNF-CEE in 2005, National Foundation for Civil Society Development, Institutional support for the stabilization and/or development of organization 2008-2010
- Corporate grants

8) Other related groups active in Croatia

- **Croatian Alliance of Hepatitis Patient Association** - founded in 2004.

Members of CAHPA:

- a) Hepatos - Osijek
- b) Prometej
- c) branch offices of CATIH “Hepatos” from Dubrovnik, Zagreb and Rijeka (they are independent legal entities)
- Cooperation with network of associations dealing with addictions illness
- Many NGOs: HIV issue, transplantation issue, Croatian Chron’s Association, etc.

Meeting in Split, 28. 06. – 01.07. 2007.



9A) Strengths

Our strengths are our values included in our vision

Hrabrost **H**ardihood (courage)

Entuzijazam **E**nthusiasm

Predanost **P**rudence (dedication)

Aktivizam **A**ctivism

Timski rad **T**eam work

Otvorenost **O**penness

Stručnost **S**killfulness (competence)

9B) Strengths

- Amendments to law regulations in the patients best interest
 - We contributed to implementation of the “golden standard” for all infected with HCV regardless of their genotype
 - We contributed to implementation of obligatory HBV vaccination for new-born babies
- Contribution to reduction of the pool of the infected with HCV and HBV.

9A) Strengths toward improved prevention

- Thanks to Hepatos, hepatitis has become the topic of public conversations in public life
- A network of inter-sector cooperation and a network of access to children and youth is established (through cooperation with elementary and high schools)
- A continuous campaign for sensitization of public and destigmatization hepatitis patients
- Organization of free-testing activities

9B) Strengths toward improved prevention

- Continuous work on informing and education of children and youth aimed at improvement of health care
- Our target is implementation of health and sexual education into schools' curriculum
- Screening
- We aim to contribute to acceptance of the best world's vaccination trends and hepatitis prevention in Croatia

10A) Challenges

- Social services delivery and health care through future INFOHEP Centre
- Widening of cooperation with NGO and public sector institutions in risk groups treatment (e.g. jails)
- Development assistance in health sub-sectors of civil society in western Balkan countries
- Civil society development in Croatia

10B) Challenges and thresholds toward support of improved prevention

- Our pressure on Government finally has results. The **national program** is in it's beginning phase and we hope it will be done until the end of this year. Actually, we are going to start marking **WHD 2008** in Croatia with **National Roundtable** on April 7th (World Health Day) on which will be presented need for such strategy.

11) Conclusions

- Hepatos through its activities in the health care has significantly improved prevention and treatment of hepatitis
- In the social services domain we provided brand new services and made accessible some previously unavailable.

11)B Conclusions

- In the field of protection and promotion of human rights, Hepatos has significantly improved the status of human rights of hepatitis patients decreasing the discrimination in the health care system and stigmatization in community.
- No one should be excluded because of his/her health status!

With all its activities Hepatos has contributed to democratization and civil society development in Croatia!

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Thank you very much for your
attention

