

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



Poland:
HCV Patients
Association
“Prometeusze”

1) History of the organisation:

- Founded on the initiative of HCV-infected patients in 2002 in Cracow. Currently the head office is in Walbrzych.
- Lack of awareness of the society in the viral hepatitis subject - 97% of infected people are unaware of their infection.
- The access to diagnostics and anti-virus treatment was limited.



2) Objectives and role of the organisation

- Reaching the HCV/HBV infected patients who are unaware of their infection.
- Spreading information on viral hepatitis (B and C).
- Health education and restraining the epidemic of HBV/HCV.
- Direct help for people with B/C viral hepatitis.
- Offering support during the time of infection – support groups, psychological help.



3) How is it organised?

- 5 regional branches.
- Represented by the Management Board.
- Non-profit organisation, volunteers.
- No business activity.
- Member's knowledge and experience, advised by medicine doctors and workers of epidemiological stations.



4) Target audience

- HCV and HBV, autoimmune hepatitis, hemochromatosis, steatorrhoeic hepatosis, etc.
- Ways of reaching organisation: Internet, information boards in hospitals, media.
- Over 2000 members. (HCV – 70%, HBV – 10%, volunteers [IT specialists, medicine doctors, psychologists, nutritionists] – 20%).



5) Services and Activities: General

Informational:

2 Internet sites; chat; discussion group; meetings; informational leaflets; national and local media; co-operation with other patients' organizations

Educational:

national actions and educational campaigns financed by pharmaceutical companies (Roche, Schering-Plough); trainings for employees of medical care institutions; education of young people

In cooperation with Polish HCV Experts Group – group of renowned scientists and doctors specializing in infectious diseases.



6) Services and Activities: Prevention

- Developing educational and informational programs.
- Co-operation with epidemiological stations (reporting the encountered irregularities or the cases of breaking the safety rules in the medical care institutions).



7) Support and Financing

- 90% - donations and grants from pharmaceutical companies (Roche, BMS, Schering-Plough, Novartis and other).
- 10% - single membership fees (not obligatory) and donations from private.



8) Other related groups active in your country

- “Life after the Transplantation” – partner, dealing on national level with all that concerns transplantology (mainly liver transplantations).
- “Against the Yellow River” – operating within 2 provinces.
- “Hepa-Help” – in 1 province.
- “WZW-SOS” – in 1 province.
- A few small organizations located by infectious disease hospitals in different cities.



9A) Strengths

- Operating on national level.
- 2000 members; 20 representatives, volunteers and people willing to help in different actions.
- Big support from the society - popularity and respect.
- Support from the representatives of the medical professions.

Support from the Members of Parliament (70 interventions for the last 6 years) and from the media (TV, press, radio).



9B) Strengths toward improved prevention

- Increasing awareness of the ways HCV is transmitted (80% of the cases happens in the medical care institutions!).
- Reporting all the irregularities to adequate supervising institutions.
- Supervising the detected HCV infections (correct statistics) and making attempts to bring into effect “The National Program Against HCV”.
- Popularizing the vaccinations against HBV.



10A) Challenges

- Low detectability of HCV infections.
- Insufficient knowledge of the society in the subject of viral hepatitis B and C.
- Insufficient interest in the matter represented by the decision-makers.
- No statistics.
- Limitations in financing the diagnostics and treatment.
- No Anti-HCV Program.



10B) Challenges and thresholds toward support of improved prevention

- Limited influence on how the health and safety-at-work rules are respected.
- Low awareness in the subject of HCV within the workers of medical care institutions.
- Low awareness in the subject of HCV in society.



11) Conclusions

- Still much to do in Poland – making statistics, spreading information, education, access to diagnostics and anti-virus treatment.
- Limited financial possibilities in order to fight efficiently with a general lack of knowledge in the matter of viral hepatitis.
- Although we have been working for years already, we think we're still at the beginning of our way. Yet, we already did a lot for the HCV-infected patients. From 2007 we also concentrate more on people with HBV.

