

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

The Netherlands
National hepatitis Centre

1) History of the organisation(s)

- Founded in 1997 by:
 - Dutch liver patient association
 - Haemophilia patient association
 - supported by liver specialists
- Lack of information for patients
- Low awareness by healthcare workers



Objectives and role of the NHC

- Improving the coordination and cooperation of activities on hepatitis;
- Documenting and disseminating the knowledge, expertise and experience;
- Advancing education and information on (the prevention of) hepatitis;
- Supporting patients with hepatitis;
- Offering expertise to healthcare workers and others;
- Offering facilities to associations, organisations and foundations that have similar objectives;
- Identifying gaps in knowledge and expertise regarding hepatitis



Organisation of the NHC

- NHC is a knowledge and information centre
 - It is a foundation
 - We don't have members
- NHC Board
 - Representatives of patient organisations, hepatologists and a independent chairman
- NHC Advisory Committee
 - Scientifics from different area's:
Medical care, occupational healthcare, public health, addiction care
- Office
 - 3 staff workers (1 fulltime, 2 part-time)
 - 3 project leaders



4) Target audience

- General public
 - Brochures
 - Website
 - Helpline
- Patients and patient organisations
 - Lobby and advocacy to government and policy makers
 - Education and support for patient self support groups
 - Individual support for patients (under antiviral treatment)
- Professionals / healthcare workers
 - Guidelines
 - Education and training
 - Website



NHC structural activities

- Information and advice
 - website, brochures, helpline, digital newsletter
- Training and education
 - Health professionals
 - GP's, nurses, public health care workers
 - Occupational healthcare professionals (company doctors etc)
- Always evidence based
 - national and international guidelines and expert opinions



NHC project activities

- National hepatitis week (education)
- National Hepatitis C campaign (awareness)
- Symposia for policymakers (lobbying)
- Project Short Chain (project HBV)
- Project centres for blood exposure accident
- Project hepatitis B and pregnancy (coordination)
- Project case study on safety systems to prevent needle stick accidents



6) Services and Activities: Prevention

- Lobby for hepatitis B vaccination for all newborns
- Lobby for free vaccination programs for (patient) groups at risk
 - Vaccination against hepatitis A and B for patient with chronic liver disease (successful completed)
 - Vaccination for all the people with a mental handicap (still working on this)
 - Vaccination for occupational risk groups (some successes, still working on that)
- NHC support to prevention of occupational exposure
 - Needle stick accidents guidelines
 - Education and training program
 - Study on the introduction of safety systems in healthcare



7) Support and Financing

- Structural activities are financial supported by:
 - Ministry of health
since 2007 delegated to the Centre of Infectious Disease prevention (CIb)
 - Pharmaceutical company's
- Projects are financial supported by:
- Different national funds
 - governmental
 - others (funds from insurance company's)
- Pharmaceutical company's



8) Other related groups active in your country

- Patient organisations
 - Patients self-support groups
- National Institute for disease prevention
 - governmental partner in the hepatitis C campaign
- Mainline
 - Support for patients with drugs related hepatitis
 - Partner in the hepatitis C campaign



9 Strengths

- NHC is working from a patient perspective
- NHC is independent
- NHC works evidence based
- NHC is accessible for everyone
- NHC is a meeting place for medical, social, public health and politic working fields on hepatitis



10A) Challenges

- Arase awareness on hepatitis
 - General public is interested in HIV and bird flew but not in hepatitis
 - A lot of hepatitis patients don't speak Dutch
- Convincing the government and politics that hepatitis is a sever health issue
 - Netherlands is a low endemic country
 - “It is a health problem from elsewhere”
- Motivating public health and first line healthcare to:
 - active detection of hepatitis
 - Develop detection programs for ethnic groups (cultural tailoring)
 - Work together in access to treatment (chain of disease management)



10B) Challenges and thresholds toward support of improved prevention

- National vaccination program hepatitis B !!!
- To see detection and treatment of hepatitis patients as
 - Prevention of severe liver disease
and
 - “Second prevention” in spreading the disease



11) Conclusions

- The Netherlands is a low endemic country
 - 0,4 % HBV and 0,15 - 0,4 % HCV
- We mustn't make the National problem bigger than it is
- But that is also the pitfall
 - More hepatitis patients through immigration
 - Less attention of politic and government
 - Less experience by general practitioners and other healthcare workers
 - “competition” with other healthcare problems
- It is our duty to see to it that all hepatitis patients gets the right to information and access to testing and treatment

