

# 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

