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

- **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 severe 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
  - “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 is 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