

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

Country/Organisation:
Deutsche Leberhilfe e.V.

German Liver Help Association

1) History of the organisation(s)

- Founded in 1987
- Patients organisation for all liver patients (hepatitis B + C, PBC, toxic causes etc.)
- Chairman o.t.b.: Prof. Claus Niederau, member o.t.b.: Prof. Michael Manns
- Scientific advisory board with 36 specialists (e.g. Prof. Zeuzem and Prof. Blum)

2) Objectives and role of the organisation

- Help patients
- Inform the public
- Cooperation with Science

3) How is it organised?

- Board of directors: 3 patients, 2 hepatologists (a majority of patients on the board is always maintained)
- Central office in Cologne, three paid workers: Manager, Counsellor/Administrator, Editor/Counsellor
- 2 voluntary workers in the office
- 13 voluntary local patient advisors in federal states of Germany
- Scientific advisory board of hepatologists

4) Target audience

- Liver patients (all diseases), their friends and families, GP's, and the general public
- Phone, fax, email, websites, patient seminars
- More than 2,000 members + contact with around 17,000 patients in the past ten years

5) Services and Activities: General

- Counselling via phone, email, fax, and letters
- Websites: leberhilfe.org, lebertest.de, hep-b.info, lebertag.org, welthepatitistag.info
- Making medical information accessible for everyone in cooperation with specialists:
 - Information brochures in everyday language
 - Patients quarterly magazine: "Lebenszeichen" ("Sign of Life")
 - All medical publications are either written, or supervised, by liver specialists
- Passing on addresses of doctors, clinics and self-help groups
- Supporting local self-help groups
- Patient seminars with doctors
- Represent patients in the making of German medical guidelines (Hepatitis B, hepatitis C and gallstones)

6) Services and Activities: Prevention

- “Impfchampion” (vaccination champ project): competition for school classes to have the highest rate of hepatitis B vaccinations
- German Liver Day: Informing the general public about liver diseases, and how to prevent them
- Counsel friends, partners and relatives of hepatitis B and C patients on transmission routes
- Cooperation with religious leaders of DITIP (Turkish Islamic Union for Religious Affairs) to inform Turkish citizens in Germany about the risks, prevention and treatment of hepatitis B.

7) Support and Financing

- Describe how the group and its activities are financed eg :
 - membership fees
 - private donors
 - health insurance companies
 - For hep-net projects: small funding by government research department
 - pharmaceutical

8) Other related groups active in Germany

Patient associations:

- Local patient advisors of Leberhilfe
- Self-help groups (mainly for hepatitis C)
- Partner patient associations (e.g. for liver transplant, viral hepatitis, hemochromatosis, cancer)

Other institutions

- German Liver Foundation
- Hep-Net
- Robert Koch Institute
- DGVS
- BNG
- GASL
- etc.

9A) Strengths

- Easy-to-understand medical information
- Medical board supervises information material to make sure it is up-to-date and correct
- Established our information material on the market and among patient groups → unified, less contradictory and confusing information than before 2001
- Neutral standpoint between patients and doctors
- Policy-making
- Efficient and structured association
- Influence in decision-making (e.g. medical guidelines)

9B) Strengths toward improved prevention

- Official organizer of German Liver Day and World Hepatitis Day in Germany
- Regular PR events and activities (e.g. radio broadcasts and press conferences)
- Well-structured websites such as livercheck.com (German)

10A) Challenges

- Lack of money
- Lack of governmental funding
- More staff needed to keep up with patient calls and projects
- There is no high-profile lobby for liver diseases as there is for breast cancer, heart diseases, or HIV
- Stigma: liver diseases are considered “dirty”. Prejudice: “Alcohol, drugs, sex”
- hepatitis patients are considered doomed (“incurable hepatitis C”) and highly infectious (“don’t touch me!”)
- Media often reinforce prejudice about liver diseases

10B) Challenges and thresholds toward support of improved prevention

- Lack of governmental prevention programmes
- misconceptions in general public distract from real transmission routes: Some people would not shake a hepatitis patient's hand, but are not afraid of having a tattoo made at the beach
- Language and cultural barriers: difficult to reach people in vulnerable migrant populations.
Solution: Cooperation with religious leaders and cultural institutes in Germany, including translations into different languages

11) Conclusions

- Deutsche Leberhilfe e.V. is the biggest liver patient association in Germany
- Central distributor of information for liver patients
- Involved in policy-making and medical guidelines
- Organisator of national awareness campaigns
- lack of funding is a permanent problem
- Difficulty in convincing the government that hepatitis B and C are an important problem
- Cooperation across national borders is more important than ever.