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

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UK
History of the organisation

• The British Liver Trust was founded in 1988 by Dame Sheila Sherlock
• It is the only national UK charity for ALL forms of liver disease
• The last decade has seen a wider recognition of liver disease in society
• Alcohol, obesity and hepatitis C has been described by the Chief Medical Officer as a ‘potential triple hit’.
• Helpline was started in 2003
• Re-launched Trust website in August 2007
Objectives and role of Trust

Mission:

The British Liver Trust aims to reduce the incidence of liver disease, and to help everyone affected by liver disease, through the provision of information, support and research.

- The British Liver Trust works to:
  - support people with all kinds of liver disease
  - improve knowledge and understanding of the liver and related health issues
  - encourage and fund research into new treatment
  - lobby for better services
Organisation of Trust

- 18 members of paid staff
- 6 volunteers
- Three departments
  - Information and Education
    - PR, publications, marketing, helpline, website
  - Fundraising
    - Community, trust and statutory, corporate
  - Operations
    - Administration/HR/finance
Target audience

- Wide reach in sectors of society
  - People who drink alcohol at hazardous and harmful levels
  - People who may be overweight and more susceptible to fatty liver
  - High risk groups for viral hepatitis
  - Hereditary/genetic conditions relating to the liver
- Supported by nearly 20 pharmaceuticals
- 7,000 stakeholders. They include:
  - Healthcare professionals, healthcare workers, patients, carers, families, occupational health
- In 2007:
  - Over 1 million visitors to our website
  - Publication sales increased by 128%
  - Calls to our helpline increased by 39% in 2007
Services and activities: general

- Patient information – we produce 23 patient information publications
- Support people and their families through the whole course of liver disease: from prevention, diagnosis, treatment, and where necessary, coping with symptoms and managing complications of cirrhosis.
- Research
- Lobbying
- Public relations and press coverage
Services and activities: prevention

- Advice through helpline and online support
- Advice through publications
- Lobbying for better public protection through vaccination and public awareness campaigns
- Project to encourage those in custody to change behaviour to protect against blood borne viruses using graphic images & language
- Advice in other languages to respond to needs of migrants at risk of viral hepatitis and its complications
- Raise awareness of liver disease through the media
Support and financing

- Trusts: 40%
- Individuals: 21%
- Statutory: 17%
- Corporate: 14%
- Community: 5%
Other patient organisations active in the UK

- Children’s Liver Disease Foundation
- C-Level
- Liver transplant support
- Mainliners
- Obstetric Cholestasis Support
- PBC Foundation
- PSC Trust
- The Hepatitis C Trust
- The Hepatitis B Foundation

Call: 01425 481320  Email: info@britishlivertrust.org.uk  www.britishlivertrust.org.uk
Strengths

• Umbrella organisation on all forms of liver disease
• Strong links with hepatologists
• Wide services for patients: support groups, helpline, publications and website (with online patient forum)
• Regularly quoted in national press – TV, print and online
• Use of high media & political interest in alcohol: springboard to wider work on liver.
Strengths toward improved prevention

• Submission to Department of Health review of liver services
• Campaign with stakeholders on hepatitis B awareness and lobbying for vaccination (B Aware initiative)
• Campaign with Government on hepatitis C awareness and screening (FaCe It)
• Support activities of the APPHG
• Key stakeholder in NICE
• Part of the coalition of health organisations regarding the harm that alcohol causes – Alcohol Health Alliance
• Other stakeholder work on hepatitis C for World Hepatitis Day and Parliamentary Group
• BBC Radio 4 programme on preventing liver disease
• Work to raise awareness about hazards of alcohol & ease of liver damage
• Plans for new prevention publications
Challenges

A graph to show the percentage change in the top five mortality conditions in the UK since 1991.
Challenges

• Stigma of liver disease: public stereotypes of liver disease as a lifestyle disease deserving little sympathy,
• Only one of 5 ‘big killers’ with no Government action plan
• High rates of inward migration to the UK from areas of high prevalence of viral hepatitis
• Confusion between different types of viral hepatitis: high rates of hep A vaccination amongst travellers and resulting mistaken sense of protection against B and C
Challenges

• Delays and barriers to antiviral treatment through NICE appraisal
• Fundraising: remains a challenge with corporates, government and individuals
• Low public awareness and education about the liver
• Crowded patient group sector: liver charities face competition and are relatively small
• Media hazard: alcohol provides an easy route to media coverage but can confirm stereotypes about liver disease.
Challenges in improving prevention

• Responsibility for prevention
  – For example: policy on injecting drug users, viral hepatitis, youth policy is split between three government departments

• Lack of approved statistics on prevalence

• Primary care physicians not incentivised or covered to provide various prevention services
  – including hepatitis B vaccination they are able to charge, very rare in the NHS and a strong disincentive for UK patients

• Lack of universal hepatitis B vaccination

• Poor awareness of risk factors for hepatitis B and C

• Some disconnect between prevention work on B and C
  – FaCe It Government campaign only covers hep C).
Conclusion

• **NHS system** offers the potential for an integrated and funded system covering prevention, diagnosis and treatment of viral hepatitis.

• Needed more than ever before with high rates of **inward migration**.

• **Policy changes** needed
  – universal hepatitis B vaccination, official prevalence studies, further public awareness campaigns to encourage prevention & screening.

• British Liver Trust is working with government, media and hepatologists as well as patients to improve protection from impact of viral hepatitis.