Viral hepatitis globally – the patient view

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President, World Hepatitis Alliance
The World Hepatitis Alliance

• Established in 2007 in Switzerland to run World Hepatitis Day

• Consists of 176 member patient groups in 65 countries

• Groups in each region elect a Regional Board Member

• Regional Board Members elect the president

• All the executive board members (including the president) must be patients and are not paid

• 4 Non-executive board members: chair of US NVHR, co-ordinator of Senegalese viral hepatitis programme, CEO of Hepatitis Australia, Director of HIV Department WHO.

• In Official Relations with WHO and Consultative Status with UN ECOSOC

This is hepatitis...
The major issues

• We feel ignored!

• Viral hepatitis not included in MDGs

• Until 2010 not one WHO employee (out of 8,000) had hepatitis in their job title. Even now the Global Hepatitis Programme has 3 people and sits inside the HIV department at WHO

• Very few governments have a plan to tackle hepatitis

• Access to good drugs has been extremely poor with far too much use of Lamivudine, failure to register Tenofovir for HBV (though registered for HIV) and HCV drugs too expensive

• The vast majority of us are undiagnosed
The major issues

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<tbody>
<tr>
<td>ASIA PACIFIC TOTAL</td>
<td>1,012,873</td>
<td>304,628</td>
<td>827,567</td>
<td>106,729</td>
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<td>AMERICAS TOTAL</td>
<td>109,025</td>
<td>74,019</td>
<td>25,044</td>
<td>1,268</td>
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<td>EUROPE TOTAL</td>
<td>123,818</td>
<td>82,009</td>
<td>35,803</td>
<td>0</td>
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<td>AFRICA &amp; MIDDLE EAST TOTAL</td>
<td>198,838</td>
<td>1,004,712</td>
<td>307,576</td>
<td>1,061,501</td>
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<tr>
<td>TOTAL</td>
<td>1,444,554</td>
<td>1,465,368</td>
<td>1,195,990</td>
<td>1,169,498</td>
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We are dying
The inclusion of HIV, TB and malaria in the MDGs led to the Global Fund and other major funding sources (UNITAID, PEPFAR etc)

Health will be much less prominent in the SDGs post 2015

Most likely one goal – universal access to healthcare

Possibility of HIV, TB, malaria, NCDs morbidity/mortality as indicators

Essential that hepatitis is included if HIV, TB etc are included

Liver cancer now second most common cause of cancer mortality

Chris Wild, IARC Director: “We cannot treat our way out of the cancer problem. More commitment to prevention …is desperately needed.”
WHO

- WHO Global Hepatitis Programme very under-resourced (3 staff vs 55-90 for each of HIV, TB, malaria)

- But offers possibility of using HIV staff for hepatitis globally

- Need for full-time focal person in each Regional Office

- Absolute need to rename department/cluster to include ‘hepatitis’

- STAC-HEP

- Member State activity at WHO 2013
  - Side meeting at 66th World Health Assembly
  - Draft resolution
WHO EB 134.R18

• Sponsored by 14 countries

• (OP) 2. REQUESTS the WHO’s Director-General:
  (3) in consultation with Member States, to develop a system for regular monitoring and reporting on the progress in viral hepatitis prevention, diagnosis and treatment;

  (7) to examine the feasibility of and strategies needed for the elimination of hepatitis B and hepatitis C with a view to potentially setting global targets;

  (10) to lead a discussion and work with key stakeholders to facilitate equitable access to quality, effective, affordable and safe hepatitis B and C treatments and diagnostics;
Lack of government response

- 47 of 126 Governments self-report having a written viral hepatitis strategy
- 4 of them had no component for prevention, either general or in a healthcare setting
- 10 of them had no component for treatment and care
- There is a big difference between having a piece of paper and a funded strategy
- There is even a big difference between having a funded strategy and putting it into action
Access

Elements of access:

- Access to testing
- Access to assessment
- Access to prescribers
- Access to monitoring
- Regulatory/licensing
- Distribution
- Price
Access strategies:

- Differential pricing
- Licence agreements to generic manufacturers
- Medicines Patent Pool
- Local manufacturing in patent-free countries (freedom to operate)
- Patent opposition and local manufacturing
- Compulsory licensing
Some questions

• HCV as a new access paradigm?
• Global funding?
• How to make hepatitis a priority health issue?
• How to make hepatitis strategies affordable for Governments?
• How to monitor progress?