

The World Hepatitis Alliance & World Hepatitis Day

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The Hepatitis C Trust – origins

- I was diagnosed with HCV in 1995 and cirrhosis in 1997
- I could find no good UK source of information and/or support (there was no UK HCV NGO)
- 4 of us with HCV decided in 1999 to set up The Hepatitis C Trust
- I was intending only to be a trustee

The Hepatitis C Trust – origins

- The Hepatitis C Trust was granted charity status in October 2000
- The other 3 founders persuaded me to become chief executive
- I did interferon treatment in 2001 / 2 & cleared HCV but developed type 1 diabetes
- The Trust now has 18 staff and 3 offices

European Liver Patients Association - origins

- In 2003 HCV Patient groups from around Europe met to share best practice
- Groups from Italy, France & Germany decided to form the European Liver Patients Association (ELPA) & begged The Hepatitis C Trust as the only UK group to join
- At its creation in 2004 I was very surprised to be asked to be President
- During this time we established October 1 as European Hepatitis Awareness Day
- I could not persuade groups outside Europe to participate
- In 2006 my 2 year term as President ended



World Hepatitis Alliance – origins

- The global situation in 2006 – inexplicable lack of awareness of hepatitis despite huge prevalence (~500 million chronically infected) and mortality (1 million+ deaths annually). No priority at WHO (no WHO staff with ‘hepatitis’ in their title)
- 2007 – I organised a meeting of patient group representatives from around the world. We decided to hold the first World Hepatitis Day to give hepatitis the same priority as HIV/AIDS (prevalence less than 40 million, mortality 2 million per year), TB & malaria
- December 2007 – establishment of World Hepatitis Alliance as umbrella organisation of patient groups
- Decision to expand the role of the World Hepatitis Alliance from just awareness-raising



World Hepatitis Alliance – areas of work

Awareness

National Policy Focus

Global Policy Focus

World Hepatitis Day - July 28



Supporting Members



WHO Resolution & Global Approach



First World Hepatitis Day May 19 2008

- *Am I Number 12?* theme
- 300 events in 47 countries
- 1200 pieces of coverage
- Reaches 150 million people
- WHO is engaged for the first time taking press conference



Awareness

- Many governments refused to take part unless WHD was official
- Need for a WHO resolution but told it was impossible – too many ‘days’ already
- Alliance and its members advocated for 18 months and in 2009 Brazil, Oman, China & Afghanistan put hepatitis on WHO agenda
- Brazil proposed a draft resolution
- Alliance advocated relentlessly with governments to improve the resolution



63rd World Health Assembly Resolution 18

- I addressed both the WHO Executive Board and World Health Assembly in 2010 urging adoption of the
- Alliance & WHO survey of hepatitis policy in the 193 Member States published May 2010 - available online at www.worldhepatitisalliance.org - showing that 80% of countries considered viral hepatitis to be an urgent public health issue
- May 2010 Resolution WHA63.18 adopted
- July 28th declared World Hepatitis Day – only the 4th disease-specific official WHO day



World Hepatitis Day 2012

- It's closer than you think concept to highlight the need for action
- 65+ countries participating
- Facebook app (live now)
- Campaign Video
- SMS campaign in Africa
- WHO & Regional Office activities e.g. hepatitis screens-savers which will pop up on personal computers of all 2000 EMR staff



This is **hepatitis...**
Know it. Confront it. Get tested.

World Hepatitis Day: 28 July
www.worldhepatitiseday.info



World Hepatitis Day 2012

- 3 Wise Monkeys concept to highlight that globally hepatitis has been largely ignored
- Guinness World Record Attempt - greatest number of people doing the 3 Wise Monkeys action on one day – July 28th
- Twitter campaign of photos of people doing the 3 Wise Monkey actions



It's closer than you think

Don't ignore it. Hepatitis is a potentially fatal disease that affects 1 in 12 people worldwide, but there are rarely obvious symptoms.

This is hepatitis... Know it. Confront it. Get tested.

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63rd World Health Assembly Resolution 18

- In addition to establishing World Hepatitis Day, Article 3.1 of the resolution requests the WHO Director-General to establish in collaboration with Member States the necessary guidelines, strategies, time-bound goals and tools for the surveillance, prevention and control of viral hepatitis;
- This means:
 - A Global Strategy
 - Regional strategies
 - National strategies



WHO Global Hepatitis Strategy

Hepatitis strategy at a glance: From WHO products to results in countries

WHO products (Attribution)		In country results (Contribution)		
Strategic axis	WHO products	Country basic operational framework		Outcome/ impact
		Plans	Results	
1. Partnership, mobilization and communication	Support for World Hepatitis Day	Hepatitis Day action	- High awareness - Absence of discrimination	- Reduced rates of new infections
	Network of collaborating centres	Centres of excellence		
	Civil society collaborations	National patient group		
	Resource mobilization strategy	Funded national plan		
2. Data for policy and action	External communication strategy	IEC strategy	- Evidence based, cost-effective policy and plans	- Reduced fulminant hepatitis mortality
	Disease burden estimates	Burden estimates		
	Impact assessment tools	National sero-survey (s)		
	Surveillance and outbreak investigation standards	Sentinel surveillance sites		
	Country profiles	Coordination cell at MoH		
3. Prevention of transmission	Research agenda	National research agenda	- Immunization coverage increased - Safe health care - Safe sex - Harm reduction	- Improved quality of life for patients with chronic hepatitis
	Guidance and tools for immunization for A, B and E	EPI schedule and SOPs		
	Safe health care standards and tools	BBV ^T prevention plans		
	Harm reduction tools for injection drug users	IDU care programme		
	Safe food and water strategies	Food and water safety		
4. Screening, care and treatment	Safe sexual practice guidance	Health promotion	- Infected patients identified, care provided and treated	- Reduced mortality from cirrhosis and HCC *
	Screening and counseling resource package	National screening plans		
	Diagnostic standards	Lab SOPs and network		
	Care and treatment guidelines for B and C	National care policy / plans		
	Training package for health care providers	National curriculum		
Equity in access to treatment and drugs	Essential medicines in list			



WHO Regional Hepatitis Strategies

- Pan American Health Organization – meeting in Columbia in March, strategy in preparation for presentation to RC in September 2012
- South-East Asia Regional Office – meeting in April & July in Delhi, strategy in preparation for presentation to RC in September 2012
- European Regional Office – strategy to be developed in 2013 for presentation to RC in September 2013
- Eastern Mediterranean & African Regional Offices – discussions ongoing
- Western Pacific Regional Office – no action. Only regional office without a hepatitis focal point



National Strategies

- Scotland – HCV action plan. Over 50% now diagnosed. Treatment rates up 150%. HBV being included
- France – started with HCV strategy, then included HBV. Now a viral hepatitis strategy
- US – brand new viral hepatitis strategy
- Australia – first HCV then HBV strategies
- Croatia and Bulgaria just announced start of viral hepatitis strategy development



National Strategies – the Alliance's 12 Asks

1. Promotion of World Hepatitis Day as the focus for ongoing campaigns which are committed to increasing disease awareness, reducing stigma and promoting prevention
2. Appointment of an individual to lead government strategy nationally
3. Development of an integrated approach for screening, diagnosis, referral and treatment, using the policies, strategies and tools recommended by the World Health Organization
4. Commitment to increase the number of persons diagnosed with chronic hepatitis B and C infections
5. Commitment to reduce hepatitis-related mortality, incorporating time-bound goals
6. Commitment to increase surveillance and publish national statistics
7. Commitment to work with patient groups in policy design and implementation
8. Commitment to examine cases of best practice internationally in designing and implementing programmes
9. Provision of affordable and confidential testing
10. Inclusion of hepatitis B vaccine in national immunization programme, including birth dose provision
11. Commitment to safe healthcare, including the promotion and enabling of safe injection practices and the strengthening of the safety of blood and blood products
12. Strengthening of efforts to protect, diagnose and treat migrant and vulnerable populations



National Strategies

- The discussions at the WHO Executive Board and World Health Assembly in 2010 focused on 2 key reasons to make WHD official: prevention and diagnosis
- Underdiagnosis remains a major feature of HBV & HCV. This will be the focus of WHD 2013
- In HBV diagnosis is vital for monitoring and prevention of HCC
- In HCV diagnosis is vital because treatments are improving rapidly, offering a cure and hence

prevention of HCC



Japan's Hepatitis Leadership So Far – Thank You!

- Free national hepatitis screening program in place since 2002. 100,000 infected found in first five years.
- National Hepatitis Law passed in December 2009 increased subsidies for treatment in April 2010.
- Comprehensive national hepatitis survey results announced at the July 23 Hepatitis Council provide a map for future action.
- Appointment of Hepatitis Ambassadors on July 18 and support for World Hepatitis Day 2012 Guinness World Record attempt with “Three Monkeys Performance” at Soccer Stadiums and other venues across Japan.



Japan's Remaining Viral Hepatitis Challenge

- 3 to 3.7 million people are infected with viral hepatitis in Japan. 50% - 70% of those have not been screened and are unaware.
- Many are over 60 years of age and cannot wait.
- 85% of those that have been screened and know they have hepatitis are still not receiving treatment.
- Over 30,000 people die from hepatocellular carcinoma / liver cancer each year in Japan.
- Recent hepatitis treatments (and more being developed) bring promise of higher cure rates and shorter treatment times, but patients can't be treated unless they are first screened.



Request for Greater Leadership by Japan

- Leadership at Home: Develop a Japan National Hepatitis Strategy. Japan should consider numerical targets for increasing awareness, screening, vaccination & treatment. Support hepatitis research.
- Leadership in Asia: The WHO Western Pacific Regional Office still has not appointed a person as hepatitis focal point to implement a regional hepatitis strategy. Japan could fund such a person or second someone to do the job.
- Leadership Globally: Support implementation of the WHO global hepatitis strategy. Japan's good track record over the past ten years makes it a successful model for others to emulate.



Major Activities While In Japan

Out of 194 WHO member countries, I chose to spend World Hepatitis Day 2012 in Japan in recognition of Japan's leadership.

July 26

- Patient meeting
- Media briefing
- Academia meeting

July 27

- Health & Global Policy Institute breakfast seminar
- Multi-partisan parliament briefing session
- Industry luncheon
- High Level Government meetings

July 28

- Speech at Japan Hepatitis Patient Alliance Symposium (at JICA)

- Join Minister of Health in Guinness World Record attempt a game



Thank You

