

HC

**NATIONAL
HEPATITIS C
RESOURCE CENTRE**

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**Head of National
Hepatitis C Resource
Centre**

- Many people living with hepatitis C today are stigmatised and face discrimination:

“I keep it under my hat due to my fear of responses. This itself causes me to live a great deal of my life “under cover”. I am unable to express my fears, unable to justify my fatigue, unable to seek understanding and support. I feel I will be placed in a situation of the “deserving or undeserving” victims of a virus. I am a silent sufferer”.

Blair M & Blair J; Living with more than Hepatitis C

– A study of hepatitis C and discrimination; Mainliners 2003: London



Aims of the National Hepatitis C Resource Centre

- **To Provide practical Support and Advice**
- **To develop a resource bank**
- **To provide Specific Advice to HCW's**
- **To promote increased awareness**
- **Advocate for Support Groups**
- **To Liaise with and respond to
Government, e.g. NICE/ National Strategy**



National Strategy for Hepatitis C

- **National Awareness raising**
- **IDU focus only**
- **Prisons??**
- **Commissioning???**
- **Rest of UK?**

- **Implementation**

Resource Centre Work Programme

- **Website/email**
 - **Advice Line**
- **Publications e.g. HCV Pack, Articles**
 - **Targeted Briefing papers**
 - **Training Programme**
- **International HCV Conference**
 - **UK Assembly on Hepatitis C**
 - **Awareness Raising**
 - **Partnership**
- **Informing Media e.g. Press Releases**

Other National Resources

- **BLT have leaflets on Hep A, B&C and general liver disease info.**
- **How's That/+ve produce the Rough Guide series**
- **The Haemophilia Society provide info for those with Haemophilia/ blood disorders.**
- **The Hepatitis C Trust website:
www.hepcuk.info**

Resource Centre is the only UK organisation with sole responsibility and focus on hepatitis C.

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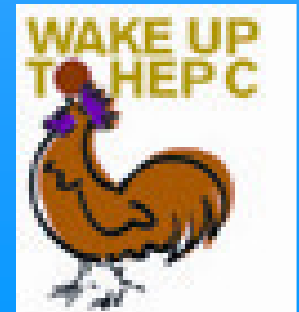
**National
Awareness Day
1st July**

**WAKE UP
TO HEP C**



National Awareness Day 1st July

- o **1st July 2003: The first Annual Hepatitis C Awareness Day**
- o **There is a collective wish across the community affected by hepatitis C to ensure there is widespread awareness and above all understanding of this virus**
- o **To date there has been little concerted effort and as a consequence we feel we need to take the initiative**



Why Have a Campaign?

- Estimated 300,000 cases (Dept of Health), though some quote higher....
- 30,000 cases have been diagnosed to date....
- Almost 90% [9 out of 10] of people living with chronic hepatitis C infection are unaware....
- Therefore they may not present until it is too late and too difficult to treat....4,000 deaths due to cirrhosis in 2000 with 2/3 under 65 years of age (CMO, 2001)....this will increase as a result of hepatitis C



National Awareness Day 1st July

- To improve testing services
- To encourage testing of those who may be at risk
- To highlight “quality of life” issues of those living with or affected by chronic Hepatitis C
- To promote effective prevention and harm minimisation

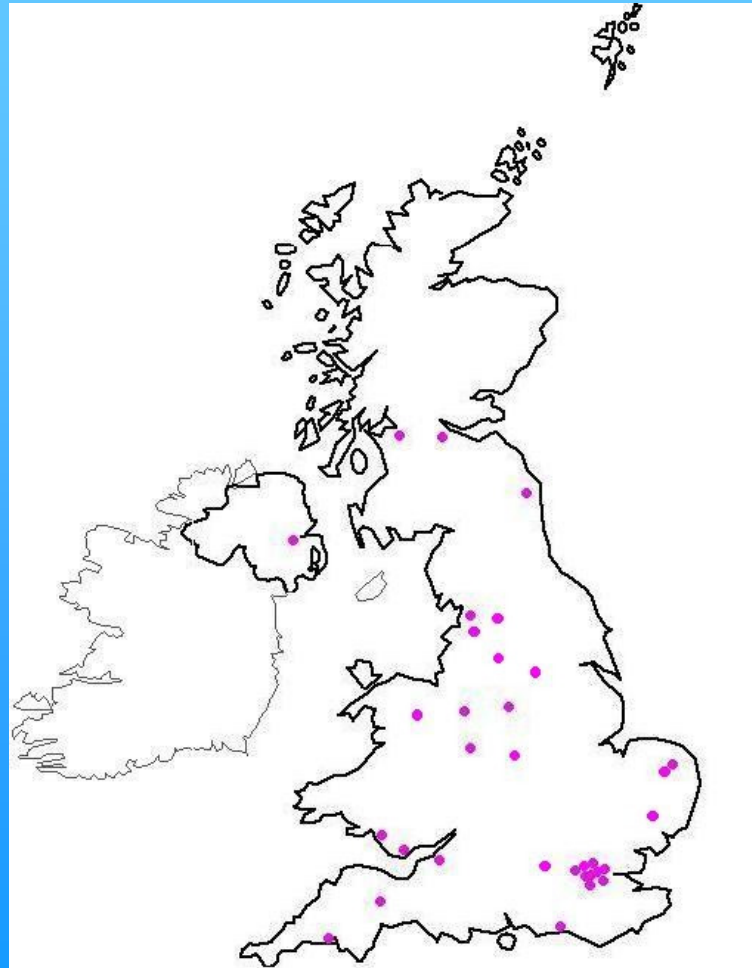


What Happened on July 1st?

- Approximately 35 regional events to raise awareness about hepatitis C
- There were a number of media stories related to National Awareness Day
- 1,000 Campaign Packs have been disseminated nationwide
- The campaign is entirely voluntary sector led with a minimum or no funding
 - partnership has been the key to its development



■ Events Held Around The UK:

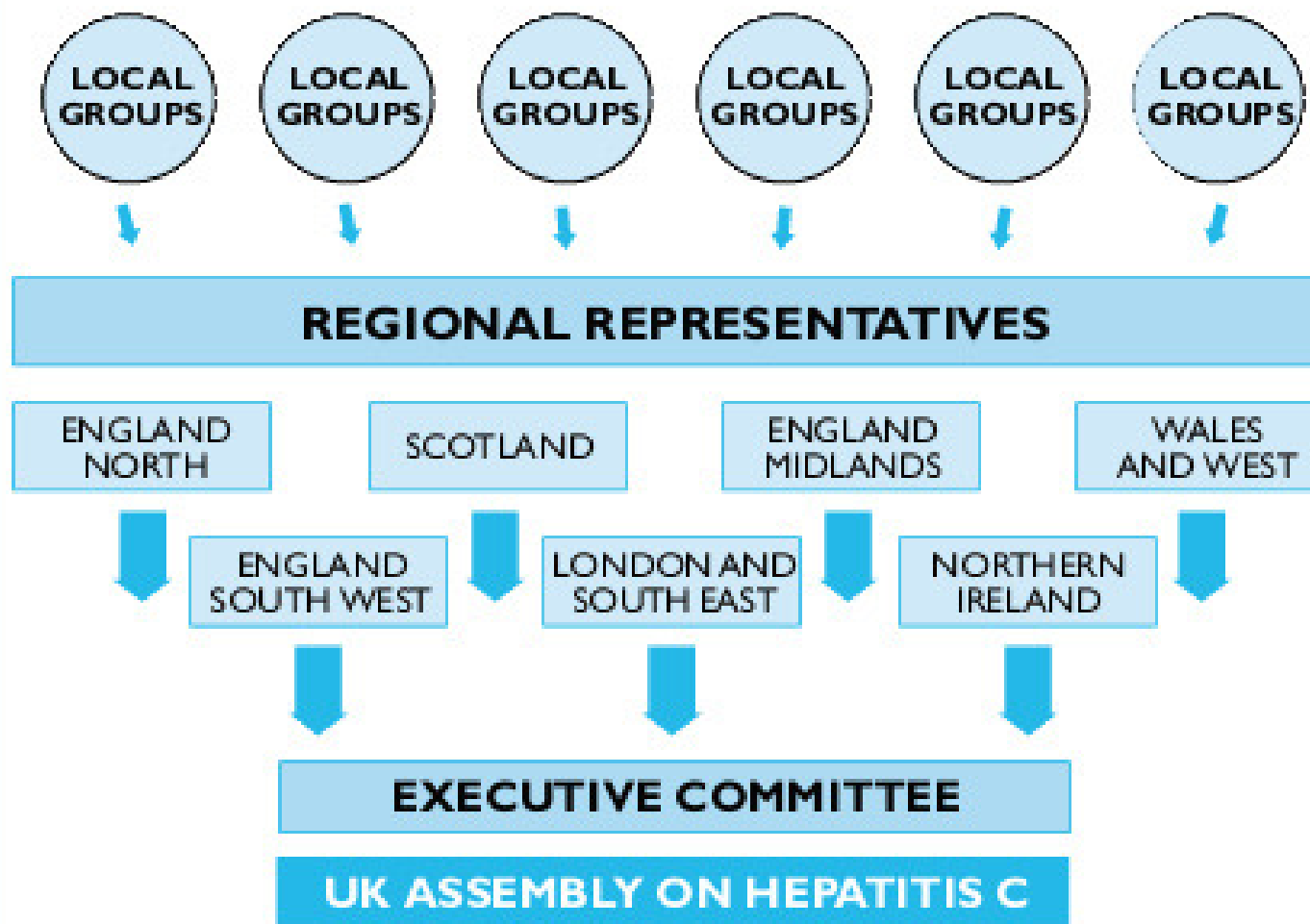


UK Assembly on Hepatitis C



- Raise Awareness
- Bring Activists/supporters together
- Facilitate Skills/information Exchange
- Promotion of New Support Groups
- Influence Policy and Practice
- Plan & Hold Mentoring Conferences

UK ASSEMBLY ON HEPATITIS C – NATIONAL STRUCTURE



UK Assembly Achievements

- **Committee set up 1999**
- **Formal launch in 2001**
- **1st Briefing Sheet distributed widely**
- **Chair co-facilitated the Discrimination Hearings.**
- **Presented at the 6th International HCV Lisbon & Australasian HCV Conference.**
- **Guide to Setting Up a Support Group**

UK Assembly Achievements

- New support groups established
- Mentoring Conferences held 2001 & 2003
- Department of Health Funding
- 2003 Communities Development Worker in post
- Membership Organisation in development
- Moving On Briefing Sheet Produced
- Major part in National Campaign

UK Assembly Mentoring Conference

- **Majority of Presenters -Positive Individuals**
- **Funded By D.A.T.'s**
- **>150 delegates–Over subscribed!**
- **New Support Groups since event**
- **Overwhelming Desire to repeat again**
- **The Patient movement in hepatitis C is not just a dream**

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