

James Lind Alliance

Note of a phone conference held on 12 December 2005, to discuss a possible working partnership in epilepsy, with neurologists active in care of patients with epilepsy and in epilepsy research.

Participants: Charles Warlow CW (chair)
David Chadwick DC
Philip Smith PS
Simon Shorvon SS
John Scadding JS

Apologies: Lester Firkins
Anthony Marson

1. CW and JS summarised the core features of the JLA, and the experience of the asthma working partnership (WP) to date. The three epilepsy clinicians had previously been sent the JLA launch document and additional published papers.
2. The epilepsy clinicians reiterated their support in general for the aims of the JLA, and a WP in epilepsy in particular. Concerns were expressed about the following:
 - (a) The large number of epilepsy support / advocacy charities, some with focused interests in epilepsy (eg SUDEP).
 - (b) Of the UK charities, Epilepsy Action is probably the largest. However, it was noted that this organisation receives substantial pharmaceutical company funding. The NSE, based at Chalfont was mentioned as a potential participant in a WP.
 - (c) The Joint Epilepsy Council (JEC) is the umbrella organisation for the UK charities, but is recognised as being rather distant from patients.
 - (d) Is there any assurance that therapeutic research prioritised by WPs might receive preferential funding, and from which funding bodies?
3. As far as the most suitable clinician organisation for an epilepsy WP is concerned, it was suggested that although the ABN represents all neurologists in the UK (and the Council of the ABN offered its support to the JLA during 2004), the UK Chapter of the International League Against Epilepsy (ILAE) specifically represents the interests of epilepsy clinicians. The current President is John Duncan and the Chair is David Josephs.
4. Margaret Jackson (Newcastle) was mentioned as another neurologist who might wish to become involved in an epilepsy WP.
5. The following action points were agreed:
 - (a) CW and JS to draft a letter to the JEC, with Lester Firkins as co-signatory.
 - (b) DC to brief Anthony Marson about today's discussions.
 - (c) SS to speak to John Duncan about the JLA.
 - (d) JS to report to the JLA Development Group (meets on 16 December) about today's discussions.

JWS 12 December 2005