Morbidity and Mortality Working Party

Membership

Dr Mike Makris (Chair)
Dr Gerry Dolan
Dr Carolyn Millar
Dr Henry Watson
Dr Jonathan Wilde
Dr Thynn Yee

Terms of reference

1. To monitor and advise on the management infections with HIV, HCV and vCJD in haemophilia
2. To review and monitor adverse events as reported on the orange card system
3. To monitor and advise on the management of thrombosis and cardiovascular disease in haemophilia
4. To monitor and analyse mortality data

Main Issues

a) variant CJD

There have been no new cases of variant CJD in haemophilia over the last 12 months. Actually the incidence of new vCJD cases in the UK population has continued to decline from a peak of 28 in the year 2000 to zero in the first six months of 2012. In view of the falling vCJD incidence rates, in contrast to what was predicted, the health protection agency (HPA) is reviewing the risk assessment calculation of risk of transmission of vCJD by blood products.

b) Hepatitis C

The new UKHCDO Hepatitis C in Haemophilia guideline has now been published (Wilde JT et al. UKHCDO guidelines on the management of HCV in patients with hereditary bleeding disorders 2011. Haemophilia 2011; 17:e77-83). A revision to this will need to be published soon to take into account the introduction of protease inhibitors for treatment. NICE has now approved both Boceprevir and Telaprevir for the treatment of hepatitis C.

The hepatitis C look-back exercise is on-going.

The Skipton Fund Appeals panel are more reasonable in dealing with applications that have been initially refused funding.

c) Vaccinations

The WP is recommending that patients with bleeding disorders who are likely to be only treated with recombinant concentrates or DDAVP do not require vaccination against hepatitis A or B. Vaccinations should be given if the patients develop inhibitors and are likely to receive ITI with plasma derived concentrates.

d) Adverse event reporting

The electronic reporting system is being further developed. Some additional questions will be asked but reporting will still remain simple. The reporting system will be similar to the European adverse event reporting system (EUHASS) and centres participating in EUHASS will only have to report their events once for both systems.

Dr Mike Makris
Chairman, Morbidity and Mortality Working Party
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