

Rare Disease Day in West Yorkshire

Wednesday 29 February 2012

BRADNET invites you to a meeting in Bradford on Rare Disease Day. We have a high prevalence of rare conditions in West Yorkshire, and this has stimulated collaboration in research, data collection, and development of services.

Following a congenital anomaly study in Bradford (part of the Born in Bradford project), January 2011 saw the launch of YHCAR, the new congenital anomaly register for Yorkshire. Catherine Whibley will report on early progress.

The regional genetics laboratories, based at St James's University Hospital in Leeds, have recently received a major grant from the Sir Jules Thorn Trust, to discover genetic mutations causing rare autosomal recessive conditions. Professor Colin Johnson will tell us about this important work.

Naz Hussain and Kerry Leeson-Beevers will report about the impact on families, and how support groups can help. Both of their organisations have been successful in influencing the provision of services and specialist clinics.

Rare Disease UK has urged national strategies for rare diseases in the 4 nations of the UK. We are hoping that the Government is about to launch a paper, which is likely to be open for consultation during a 3 month period this spring.

Health authorities and primary care trusts are having to cope with major changes, against a background of financial restraint. We hope to hear about the place of rare conditions in local health planning. The meeting will end with an opportunity for open discussion about the issues raised.

For more information about this free meeting, contact Donna Tattersall at donna.tattersall@bradnet.org.uk or on 01274 224444 (when prompted dial extension 528). There may be room for a few posters or tables for leaflet display by support groups (small payment required).