

## **REPORT ON ANNUAL CONFERENCE BRADFORD - OCTOBER 2003**

Our General speaker was Dr. John Walter (Manchester). He described the state of care for glycogen storage disease (GSD) sufferers in the north of England. Based at the Willink Biochemical Genetics Unit, Manchester he outlined the many disparate services required by GSD patients and explained how difficult it was for individual medical personnel to be maintain their knowledge in such rare disorders when they meet so few. He argued that only specialist centres could gain the necessary experience and commit time and effort for training.

Dr. Walter expressed his desire to improve services in surrounding towns and was worried that the development of adult services is too slow. The vulnerability of specialist centres due to lack of understanding amongst government commissioners and a shortage of specialised staff was also highlighted. He stressed that patient groups such as our Association for Glycogen Storage Disease (UK) can play an important role by applying pressure on the UK government to improve resources for these important services.\*

**Dr. John Walter/Allan Muir**

\*Following an announcement by the Minister for Health John Hutton in March 2002, the Department of Health (DoH) issued a consultation document in September 2002 on Commissioning Specialised Services in London. The first question they asked was: "Should all PCT's be required to set up joint PCT subcommittees with delegated authority for the purpose of managing specialised services commissioning?" The problem with rare disorders such as GSD is it is too rare to list separately although such diseases as Cystic Fibrosis etc are specifically listed.

Check out the DoH website for the latest listing of NSCAG services