

## **Planning for a National Leukodystrophy Service**

### **Dr John Livingston MD**

Leeds University Teaching Hospital staff. . Leading the negotiations with NHS England to develop a nationally commissioned leukodystrophy service

Background to the proposal

- Many patients with Leukodystrophies are undiagnosed
- Long diagnostic odyssey of investigations
- Many MRI images sent out of the UK for a second opinion
- Lack of concentrated expertise in UK

In 2008 the Department of Health approached the British Paediatric Neurological Association (BPNA) to consider a rare disease for National Commissioning. BPNA consulted members and several disease groups and proposed:

AIMS

- Build national expertise
- Improve time to diagnosis
- Avoid second opinion
- Avoid lengthy and painful investigations

This was a long process involving changes of government and NHS bills. It is still going forward, with the current proposal for three National centres, North, South and Central. Diagnostics will be virtual, with a Multi-Disciplinary Team in each centre. Also, there was a need to maintain a disease register.

Benefits

- Early diagnosis
- Management/access to information
- Treatment
- Research
- Disease Registry
- National and international collaboration

## Benefits to MLD Patients

- Raised profile of MLD
- Concentration and development of expertise
- Improved access to specialist advice and care