NEUROIMAGING IN NEUROFIBROMATOSIS TYPE 1: OUTCOMES FROM A TARGETED APPROACH-EXPERIENCE OF A SINGLE TERTIARY CENTRE

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Aims Routine imaging is not recommended for patients with neurofibromatosis 1 (NF1) and a clinical approach is used to guide need for investigations. We aimed to determine clinical characteristics and symptoms which were most commonly associated with abnormalities on neuroimaging in children with NF1.

Methods We analysed 100 consecutive patients with an established diagnosis of NF1 seen in a tertiary NF1 clinic. Records of patients who had undergone imaging studies were reviewed to determine clinical presentation and associated comorbidities, along with neuroimaging results.

Results 59/100 children with NF1, (M:F =55:45; median age 11.6 years (range 9 months–21 years) underwent cranial MRI scanning. The most common indications for MRI request being visual disturbance or abnormal fundoscopy (37%), concerns regarding growth or puberty (13.5%) and headaches (10%). 91% had an abnormality on MRI, 66% of which were UBOs (unidentified bright objects). 13(22%) optic pathway gliomas, 7 (11.8%) non-glioma CNS tumours, 8(13.5%) had other CNS abnormalities. 10/59 (17%) required surgical intervention. In 5/59 (8%) children the scan was normal. Patients with learning difficulties and neuro-developmental disorders (such as ASD/ADD) had a significantly higher incidence of UBO (90% vs. 40%; p < 0.001). There was a higher incidence of non-UBO CNS lesions amongst the group with learning difficulties. 2 asymptomatic patients had incidental findings on scans done for other reasons; 1 of them required surgical intervention.

32/100 children had MRI spine, common indications being scoliosis (40%) and back/neck pain (28%). 34% of these scans were abnormal. Chiari malformation, cervical syrinx and dural ectasia were the most common abnormalities. 5/27 (18%) needed scoliosis surgery.

Conclusion Targeted imaging in our cohort identified a significant proportion of abnormalities. Children with NF1 and associated neurodevelopmental conditions (learning difficulties, ASD, ADHD) were more likely to have an abnormality on the scans, thus warranting a lower threshold for neuroimaging. For the efficient use of resources, a high index of clinical suspicion is essential for early identification of NF1 related complications.

G199(P) AUDIT OF INFORMATION PROVIDED TO PARENTS OF CHILDREN WITH EPILEPSY

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Introduction Epilepsy is common in children. Diagnosis may impact negatively on the family. Witnessing a seizure can be very frightening. A wide range of emotions and reactions from the parents are reported once the diagnosis is made. High quality information for the family provided on time can be very beneficial. Involving the child and family in decision making is associated with good outcome and improve compliance.

Aim There are risks associated with epilepsy. Many professionals pay attention to medical management (medication) once a diagnosis is made. However, needs of the child and family for high quality information is ignored. NICE guideline has highlighted what information needs to be provided to the family and safety measures to be taken. As with no epilepsy clinic locally, I performed an audit to look into our practice and to check it against the standards set by the NICE and National service