Clinical Management Protocol - Neuroblastoma [DH Quality Measure 09-7A-118]

**Carers present Child / Y.P. <16yrs with symptoms** (specific and/or non-specific) to:
- GP
- Emergency Dept @ DGH, POSCU or PTC

**PRIMARY CARE ASSESSMENT**
Mass / hypertension / unwell and suspicion of a tumour or malignancy.

**SECONDARY CARE ASSESSMENT**
Abdominal / paravertebral mass / suspicion of neuroblastoma or renal tumour

**Urgent Telephone Referral** to on call paediatric oncology / haematology consultant. At Principal Treatment Centre, Leeds Children’s hospital (preferred method of referral).
- Or Urgent Cancer Referral Form (Fax)

**Transfer to Principal Treatment Centre (Leeds Children’s Hospital)**
- Transfer to PTC for investigation / further management within 24-72 hours. Urgency advised by PTC team after discussion with referring clinician. Any symptom of orbital or spinal cord compression needs immediate transfer.
- Copies of previous imaging to be sent with patient & referral letter

**Diagnostic investigations**
- Further investigations performed by LTHT team including urine catecholamines, LDH, ferritin, NSE and biopsy or primary resection to be decided after discussion with specialist surgeons. Complete staging to include CT chest, MRI abdomen and pelvis, MIBG, isotope bone scans and bone marrows. Tissue must be sent to cytogenetics laboratory, Newcastle.

**Diagnosis of Neuroblastoma Excluded**
- Referral to other oncology pathway, other specialty or refer back to referring hospital as appropriate.

**Complications**
- Feb Neutropenia - see below *
- Blood product support - see below *
- Others: Admit / transfer to PTC
- PICU when necessary
- Urgent End-of-life care on treatment

**Hickman or Portacath Insertion by specialist paediatric surgeons.**

**PRIMARY NEUROBLASTOMA DIAGNOSIS –**
Clinical Trial entry or follow standard treatment according to age, stage, MYCN and histology, as per national guidelines.
Patients staged according to the INRG as L1, L2, M or Ms

- **High risk patients**
  - All MYCN amplified (apart from L1) and all M >1 year.
  - Treated according to the HR-NB1 SIOPEN clinical trial.

- **Non high risk patients**
  - Patients need detailed MDT discussion within PTC involving oncologists, radiologists and specialist surgeons.
  - Treat according to the CCLG guideline - Treatment of patients with low / intermediate risk neuroblastoma. (www.cclg.org.uk)
  - Generally
    - L1 resected then follow up
    - L2 chemotherapy then resection
    - M<1 yr chemotherapy then surgery
    - Ms Observe and chemotherapy only if symptomatic or progression.

- **Very Low Risk Patients**
  - Infants (<3/12) with antenatal or neonatal diagnose adrenal masses need close observation, including regular abdominal ultrasound scan and urine catecholamines.

**In-patient Induction**
Chemotherapy followed by stem cell harvest in PTC

**In or outPatient**
Chemotherapy if indicated and given in PTC

**Surgery**
PCT – referral to specialist paediatric surgery team
**Febrile Neutropenia Admissions**
Admit PTC or POSCU which accepts patients for febrile neutropaenia treatment (Hull, York, Calderdale). Dependent on diagnosis, post code, patient choice, severity and complications then patient may be transferred back to PTC from POSCU & on rare occasions may require PICU retrieval team.

**Day Case Blood Product support**
Packed Red Cells and/or Platelets at PTC, or POSCU Levels 1, 2 or 3 (Hull, York, Calderdale, Scarborough, Airedale)

**End of Treatment Assessments at PTC**
- End of treatment (EOT) appointment - discuss EOT summary and care plan (meeting involve patient, carer, POSCU rep, liaison nurse) and documents distribute to primary care.
- Removal of Central Venous Access Device if fitted – surgical admission
- Follow-up as detailed in care plan PTC / POSCU

**Long Term Follow Up (LTFU) and Transitional Care / Survivorship Programme**
- Transfer to LTFU MDT as per CCLG Guidelines or trial protocol at 5 years.
- Stratification of type of follow-up according to NCSI project linked to local policy
- Refer to late effects MDT for transition to LTFU Clinic at 5 years off treatment
- Survivorship & Rehabilitation

**Self Referral**
Clinical review of any patient with concerns related to original neuroblastoma or treatment.

**Relapse / Refractory disease**
Move to new individualised pathway
Consider eligibility for phase I / II Clinical Trial
May include palliative care pathway

**Radiotherapy - In PTC by specialist paediatric clinical oncologists in PTC**

**Radiotherapy - Only if L2 and >18/12 and poorly differentiated histology in PTC**

**Cis RA, ch14.18/CHO +/- IL-2 according to the HR-NB1 clinical trial protocol, in PTC**

**Cis RA only if >18/12 and poorly differentiated tumour, in PTC**

**High Dose Chemotherapy - autograft procedure - PTC**

**The Leeds Teaching Hospitals NHS Trust**

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