Referral pathways for patients with Vein of Galen Malformation @ GOSH

Vijeya Ganesan & Claire Toolis - revised December 2011

From 01/04/2006, treatment for vein of Galen malformation in the UK has come under the auspices of the department of health National Commissioning Group, with 2 designated treatment centres in the UK, namely GOSH (Dr S Brew) and Glasgow (Dr JJ Bhattacharya).

As is the policy for all children admitted to GOSH, all children with vein of Galen malformation will have a named GOSH consultant who will take responsibility for the clinical care of the patient. For children requiring urgent inpatient admission this may be an intensive care consultant, a cardiologist or a neurologist, depending on the child's needs. The GOSH clinician accepting the patient will advise on the optimal mechanism for transfer to GOSH (for neonates in heart failure it is anticipated that ordinarily CATS transfer will be requested). Antenatal referrals should be directed to the fetal medicine team at UCLH.

Acute presentation: e.g. heart/multiorgan failure antenatal diagnosis

These children will require urgent admission and intensive care.

- Clinician taking referral *must* discuss with:
- duty consultant neurologist
- •duty consultant cardiologist
- duty NICU consultant
- •duty consultant neurosurgeon
- Dr Brew
- •2. Decision to accept referral will be made jointly by
- •duty intensivist and Dr Brew if child needs intensive care
- •duty neurologist/neurosurgeon and Dr Brew if child not requiring intensive care
- 3.If Dr Brew will not be available in a timely manner, the GOSH clinician taking the referral (usually the duty neurologist) will direct the referral to the other NCG treatment centre in Glasgow.

The clinician accepting the referral must inform interventional radiology as soon as possible (x0491 or list coordinator)

Subacute presentation e.g. acute hydrocephalus, "vanishing white matter",

These children are likely to require admission but unlikely to require intensive care.

- The clinician taking the referral should discuss the referral with:
 duty consultant neurologist
- •duty consultant neurosurgeon
- duty consultant cardiologist if appropriate
- Decision to accept referral will be made jointly by duty neurologist/neurosurgeon and Dr Rrew
- 3.If Dr Brew is not available, the duty neurologist/neurosurgeon will accept the referral and arrange a clinical assessment and appropriate neuroimaging for the patient. Following this, a decision will be made either that (i) treatment can be deferred till Dr Brew's return (ii) treatment is required more urgently. If this is the case then the duty neurologist will contact the Glasgow service

Non-urgent presentation: e.g. well child with macrocephaly

These children will usually be initially evaluated in outpatients.

- •The outpatient clinic is run by Dr Ganesan, Dr Brew/Dr Robertson and Miss Ternier.
- •All referrals should be made to Dr Ganesan who will discuss with the team
- •Referral guidelines, contact details and information about the clinic is available for referrers on
- http://www.gosh.nhs.uk/clinserv/nndis.htm
- •Patients will be offered the next available appointment in the monthly neurovascular clinic
- •Any neuroimaging should be sent to Dr Ganesan prior to the appointment

Contact details for NCG Vein of Galen - GOSH

Dr Sanjay Bhate Consultant Neurologist Great Ormond Street Hospital London WC1N 3JH 0207 405 9200 - 5819 Ms Claire Toolis Clinical Nurse Specialist 0207 405 9200 - 0569 Claire.toolis@gosh.nhs.uk

Out of Hours contact Oncall Duty Neurolgist via switchboard - 0207 405 9200

Antenatal Referrals

These patients have been diagnosed to have vein of Galen malformation on antental ultrasound.

The referring team (generally obstetrics/foetal medicine) should contact the foetal medicine unit at University college Hospital and the patient should be booked into joint foetal medicine neurology clinic condected by Dr. Janet Rennie and Dr. Chittie. Dr. Brew will join Dr. Rennie for antenatal counselling.

. If decision is made to treat the baby after delivery; In utero transfer should be arranged for delivery in UCLH under the obstetric team at UCLH (including from within London) It is likely that these babiels will be delivered prematurely and likely to become very sick after delivery. Following clinicians should be informed once referral has been accepted and EDD is known **Duty consultant Neurologist Duty Consultant Neurosurgeon** Duty consultant Intensivist

Interventional radiology

Duty Consultatn Neuroradiologist.

Contact details for NCG vein of Galen Fetal **Medicine Unit at UCH**

Clinic on Monday-foetal medicine Dr. Rennie and Dr. Chittie MDT foetal neurology clinic

Referral contact address:

Fetal Medicine Unit 1st Floor, Elizabeth Garrett Anderson Wing University College Hospital 235 Euston Road London NW1 2BU

Telephone: 020 3447 6150

Mobile: 07892 147 717 (referring hospitals

only not for patient use) Fax: 020 3447 6195

E-mail: fmumidwife@uclh.nhs.uk

Contact details for NCG vein of Galen service in Glasgow:

Dr J J Bhattacharya Consultant Neuroradiologist Institute of Neurological Sciences Southern General Hospital 1345 Govan Road Glasgow

G51 4TF Tel: 0141 201 1100 Fax: 0141 445 5273

Or via the duty consultant paediatric neurologist at RHSC, Glasgow. (0141 201 0000)

Irene McArthur Neurology Nurse Specialist Fraser Allander Unit Royal Hospital for Sick Children: Yorkhill NHS Trust Glasgow **G3 8SJ**

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