South West Midlands Newborn Network Down syndrome Care pathway

Age	Professional	Tasks
Birth	Consultant Paediatrician/ neonatologist	Neonatal examination Confirm Down Syndrome Counselling of parents by consultant Give written information to parents form DSA (DSA pack) Provide information on Down syndrome care pathway Blood for chromosomes and FBC (Recruit to Oxford haematology study if a study centre) Notify midwife, obstetrician, GP, HV Cardiac assessment (full examination and pulse oximetry). Ideally Echocardiogram prior to discharge but within 4 weeks otherwise, unless cardiac signs when needs to be asap. Check visual behaviour and red reflexes for congenital cataract . Low threshold to refer to ophthalmologist if any concerns. Refer Community Paediatric team Who will refer to multi-disciplinary team. Full detailed referral required with copies of any other referral letters eg to ophthalmology, cardiology. Important to state who has copied of any correspondence. Refer to Early Support Services (referral form in Appendices) Specialist advice for feeding provided by nurse specialist/dietician with referral to speech and language therapy for specialist dysphasia assessment where necessary Provide parents with information about additional sources of help and advice (if not already done so) Ensure Down Syndrome insert is in PCHR (Can get from Harlow printers). Remove other

		growth charts. Ensure growth parameters are plotted on Down syndrome growth chart in hospital medical records
Audiology	NHSP (National Hearing screening Programme)	Babies with Down syndrome should be automatically referred for audiology follow-up. Need to check this has happened.
Within 5 days	Midwife	Routine Guthrie test
2-4 weeks	Consultant Paediatrician	Follow-up appointment • Feeding / growth ensure Down Syndrome insert is in PCHR and growth parameters plotted on down syndrome growth chart • Cardiac re-assessment as appropriate • Check red reflexes for congenital cataract • Refer to community SALT as necessary (form on community Health website) or enquiries via Speech and Language Therapy, Sutton Cottage Hospital, 27a Birmingham Road Sutton Coldfield, B72 1QH. Tel: 0121 465 5419 • General well-being of baby and family
6 weeks	HV / GP	Routine Routine Child Health Service - primary birth visit. CHS • Plot growth on Down syndrome chart
8 weeks	HV/GP	Primary immunisations
3 – 4 months (Will see by 18 weeks) In liaison with disability social worker attached to CDC	Community Paediatrician	Initial assessment • Developmental assessment. • Referral to physiotherapy as appropriate • Refer to ENT ((Miss C Tzifa, ENT consultant at BCH) and check that has been reviewed by audiology • Refer to ophthalmologist if not already referred. • Refer to community SALT if not already done • Offer information on services available if not already done • Refer to Early Support Services (ESS)/ portage if not already done • Consider Common Assessment Framework (CAF) referral as appropriate (for children with complex social situations). Complements ESS

Initial management guideline for babies diagnosed with Down Syndrome either antenatally or postnatally

Diagnosis

- Parents of babies diagnosed antenatally to have Down syndrome should be seen antenatally by a neonatal consultant, and as many arrangements (as are feasible), for postnatal care should be put into place. If the baby has structural abnormalities which may require NNU admission, parents should be given the opportunity to visit the unit.

- All babies suspected of, or known to have, Down syndrome should be seen by a named senior paediatrician as soon as is feasible after birth, in a private location. This should be within 12 hours of the first suspicion of diagnosis. If the diagnosis of Down syndrome is suspected, the next person to examine the baby should be a senior paediatrician, (unless there is an emergency situation and the baby warrants immediate emergency care). Multiple consultations by a number of different doctors should be avoided.

- Interpreter services should be used for non-English speaking parents.

- This is a very challenging time for parents and the team need to remain sensitive and support the needs of the parents.
The joy of the birth, is at odds with the grief experienced as a result losing the “normal” baby. Many parents find the conflicting emotions very difficult to cope with, even when they are very accepting and very loving towards their baby. The realisation of having a baby with a major chromosomal abnormality and significant developmental and health implications, impacts on different individuals in a number of different ways. Apart from grief, some parents may be angry and may initially reject the baby; others are remarkably accepting.

- Both parents should be present during the consultation as far as possible and as appropriate. (However, Mothers may become unnecessarily distressed if they have to wait too long for a joint consultation, and so a balance must be sought between ensuring optimal support for mother by her partner, and heightened anxiety while awaiting a planned consultation). An explanation of the baby’s features and diagnosis should be delivered sensitively. Parents should be given the time they need to absorb the news. Repeat visits may be necessary to deal with questions and distress.

- The same consultant should continue to see the baby and parents until discharge. In cases where this is impractical, there should be a clear hand-over to another named consultant, ideally one who will be following up the baby as an outpatient concurrent with handover to a community team.

- Refer baby to appropriate community paediatric team. Note that a full detailed summary will be required. It is important to attach copies of any other referrals. Also to state who has been copied in to all correspondence and referrals:

Phone Central Booking services:

- For Birmingham babies: Springfield Centre, Raddlebarn Rd, Selly Oak B29. Tel: 0121 465 8270 (will be able to say where baby will be referred to).
- For Solihull babies: send to Community Paediatrics at 3, The Green, Solihull. 0121 746 4476

- Also Refer to Early Support Services – ISEC Base, Perry Common rd, Birmingham B23 7AT 0121 303 0100

- Written information should be provided (DSA New Parent Information Pack).
  - (http://www.downs-syndrome.org.uk/images/stories/DSA-documents/Publications/general/new_parents_guide_2006.pdf).

Telephone the DSA (0845 230 0372 or email us at info@downs-syndrome.org.uk) to obtain a full information pack and list of local contacts.
Many parents find much support from local parents contacts

Initial Specific problems

- Babies with Down Syndrome may not feed well in the early days of life. Mothers who wish to breastfeed should be encouraged to express milk at an early stage to facilitate lactation and provide milk which may be required to "top-up" a baby who is not latching well. For those who wish to formula feed, there may be some benefit to using special teats.
- SALT may be helpful while baby is still in hospital. If problems arise in the community should make a Community SALT referral. It is important to ensure that feeding has been established and that the baby has not lost >10% of body weight prior to discharge.
- The relevant correct growth chart (male/female), for babies with Down syndrome should be inserted into the Parent-held Child Health Record Book ("Red Book").

Investigations

Chromosomes
Routine assessment by the genetics service is not required unless there is doubt about the clinical diagnosis or there are other unusual features.
Referral to genetic service is recommended for discussion of recurrence risk, particularly if the trisomy is due to a chromosome translocation or if other chromosomal abnormalities are found on karyotype examination.

- Other investigations to be completed and/or arranged prior to discharge:
  - Full Blood Count
  - Echocardiogram
  - Audiology assessment will be within the NHSP but need to check that it has happened. Ophthalmology referral if any concerns re visual behaviour, red reflexes or cataract

No formal thyroid function tests are required other than the newborn screening card.

- Discuss the Oxford Haematology research study with parents (for those units contributing patients to the study).

- Follow-up at least once at 2-4 weeks of age (or sooner if feeding problems and weight issues) in local clinic, even if follow-up is being undertaken by community team. Will be likely to need further follow-up if ongoing acute medical needs eg cardiac, failure to thrive.

- The consultant should phone the GP and the discharging nurse should phone the HV to inform them of the diagnosis as well as send discharge letters. A copy of the

discharge letter should be given to the parents detailing clear arrangements for follow-up and contact details of healthcare support workers.

Neonatal Checklist for management of babies with Down syndrome

Neonatal/paediatric consultant Date (s) seen	
Community consultant Referral made/ date Who by	
Earl support Services referral Referral made/ date Who by	
Information leaflets given DSA SWMNN care pathway ESS	
HV contacted Name Date/time Who by	
GP contacted Name Date/time Who by	
ECHO Date/time	Findings
FBC Haematology study (If applicable)	
NHSP Date/time	Result
Opthalmology	
Follow-up arrangements	