

NEONATAL FOLLOW-UP

Procedures for Discharging a Baby

Parents of babies who stay on the Unit are fully supported during their baby's stay on the Unit, which has a philosophy of family-centred care. Families are often overwhelmed with anxiety when they first take their babies' home. It is therefore important to fully prepare and support families well in advance of their baby's discharge and to provide a smooth transition from hospital to home.

Aims:

1. To initiate a planned discharge programme from admission onwards, providing effective communication links with the primary health care team and any other agencies involved, for example, Social Care and Health.
2. To confirm that the family is confident about assuming the responsibility of caring for their baby.
3. To ensure that the baby is clinically fit for discharge.

Practice:

1. On admission of a baby to the neonatal Unit, the ward clerk will inform the health visitor base (identified at present through GP attachment, except for the Sure Start area).
2. The family's health visitor will then make contact with the Unit to obtain more information about the baby.
3. Weekly, the ward clerk or nursing staff will telephone the relevant family health visitors to enable the appropriate staff members to give updated information on all babies present in the Unit. All communications with the health visitor should be documented on the psycho-social sheet, and on the green sheet.
4. Health visitors are encouraged to visit the baby and, if possible, meet the parents on the Unit or at home before the baby is discharged from the Unit.
5. When the discharge date is known, the Unit staff will attach a "Discharge Pack" to the baby's care plan and put it into action.
6. Staff on the Unit will discuss with the parents/carers the proposed discharge date and any concerns they may have about taking their baby home. Unit staff will remind the parents that they will have to bring suitable clothing for the baby and a car seat to take their baby home in.
7. Unit staff will give the parents/carers the "Going Home" information booklet.
8. Both parents/carers should be encouraged to stay in Unit flat before discharge to ensure that they are confident in caring for their baby.
9. Ensure Parentcraft sheet is up to date and completed by discharge.
10. Drugs to take home should be ordered 48 hours before the date of the baby's discharge. Controlled drugs should be stored and signed for according to Trust policy.
11. When the discharge date is known, nursing staff will contact the health visitor's base. The named HV will respond promptly and discuss the discharge plan with a nurse from Unit. If

a baby is discharged from the Unit during the weekend, the Unit will notify the HV base on the Monday morning following the discharge.

12. Prior to the discharge, health visitors will undertake a home assessment for all babies born under 32 weeks gestation or with a birth weight below 1500 grams. These babies will receive a targeted health visiting service. In addition, a home assessment by the health visitor should be made for families where the parents' medical or social history may have an impact on the baby's healthy development.
13. The health visitor must be able within the first few days after discharge. If the baby is less than 28 days old, the midwife should be contacted and informed of the discharge arrangements.
14. If indicated (please see separate guidelines) the Paediatric Community Nurse (PCN) based at the Children's Hospital should be contacted by the Unit to arrange home visits. This contact should be made as early as possible and the PCN should be invited to meet the family on the Unit before discharge. A copy of the discharge letter should be sent to the PCN at the baby's discharge from the Unit. The PCN and the health visitor should share information relevant to the baby's care.
15. If the child's circumstances require a discharge planning meeting (e.g. no antenatal care, mental health issues, substance misuse or previous child protection concerns), then this meeting should be arranged to include the Registrar or Consultant, an experienced neonatal nurse who has cared for that baby, the family health visitor, the social worker, the parents and any other key professional involved with the family.
16. If needed, (see protocol) the baby should be examined by the ophthalmologist. All babies should have audiology testing as per protocol prior to discharge or alternatively, an appointment should be made for a later date and recorded in the Parent Held Child Record (PHCR, red book).
17. Some babies may need immunisations prior to discharge (see immunisation guidelines). All immunisations/vaccines given should be recorded in the PHCR.
18. Check that the baby has had a PKU/thyroid function test and that this has been recorded in the PHCR.
19. The medical staff should be reminded, with as much notice as possible, that a discharge summary is required.
20. A medical discharge examination is performed.

Day of discharge:

1. The baby is weighed and the weight recorded in the Admission Book and the PHCR.
2. The parents will be given a copy of the SEND medical discharge summary, which the medical staff will discuss with them. The HV and GP can then access this if required, so parents are advised to keep this in their PHCR.
3. The Neonatology secretary will send a discharge summary to the baby's GP. A copy of the summary will also be sent to the health visitor.

4. The discharge note and prescription form (TTO form) should be distributed as indicated on the bottom of the form.
5. A summary of the baby's progress should be recorded in the PHCR, including weights plotted on the centile chart.
6. For a baby under 28 days old, the CommUnity Midwife should be informed. Contact with the midwife is made through the CommUnity Midwives' office: Monday to Friday, or at weekends by contacting Level 12.
7. UNIT staff must ensure that arrangements are being made for an outpatient appointment.
8. The baby's discharge date and correct discharge address must be recorded by UNIT staff in the admissions book.
9. Metavision summaries to be created and filed by ward clerks.

Early Discharge from Labour Ward

1. All newborn infants should have a physical examination by a Neonatal SHO/ANNP prior to discharge.
2. The examination should preferably be performed when the infant is at least 2 hours old to allow for cardiorespiratory stabilisation. If a problem is detected, the SHO should ask the Registrar to review the baby prior to discharge. Arrangements must be in place for follow up of the problem.
3. The SHO should be notified as soon as possible if a mother wishes for a 6 hour discharge. Between 5.00 pm and 9.00 am weekdays, 3.00 pm - 9.00 am Saturdays and Sundays there is only one Neonatal SHO on duty and their primary responsibilities are to the patients on UNIT and resuscitations in Labour Ward. When there is a more urgent duty, they may not be able to perform the neonatal discharge check when requested.
4. When a Midwife requests the SHO to perform discharge check, if the SHO is not immediately available she should request an estimate of how long it will be until the SHO is available and ask the parents to wait.

1) Follow-up of babies admitted to UNIT:

Consideration should be given to follow-up for all babies admitted to the Unit. It may be discussed with a Consultant and at the Wednesday Psychosocial Meeting.

Follow-up should be guided by the baby's needs:

- a) **Short term medical issues:** follow-up of jaundice screens for example.

Baby Clinic (or equivalent if discharged back to local care). Only one or two visits should be necessary before transfer to another clinic if further follow-up is indicated.

Efficient handover to GP, Health Visitor, Midwife or Community Paediatric Nurse should eliminate the need for most short term follow-up.

2. High risk pre-terms - all babies born at < 32 weeks and/or <1500g.

The purpose of preterm follow-up is to screen a population of infants at high risk for neurodevelopmental problems thus allowing early detection and intervention.

Continued support may be provided for families and feedback on outcome of Unit graduates will be gained. Appointments will be arranged according to corrected gestational age.

Indication	Criteria		1	2	3	4	5
Prematurity	<29w <u>or</u> <1000g	All	6w	3m ²	6m ²	1y ²	2y ¹
	29-31 ²⁶ w <u>or</u> <1500g	All	6w	3m ²	6m ²	1y ²	
	>32w	Only if received intensive care or evidence of neurological injury	6w	3m ²			

2. >32 weeks and >1500g with severe neonatal illness

Those requiring prolonged ventilation, exchange transfusion, apparent perinatal hypoxic ischaemic encephalopathy, known intracranial pathology, abnormal neurology, birth trauma, marked IUGR or congenital abnormalities.

IUGR		weight <2 nd centile	6w	3m			
HIE	Grade 1	None					
	Grade 2	All	6w	3m ²	6m ²	1y ²	
	Grade 3	All	6w	3m ¹	6m ¹	1y ¹	2y ¹
Seizures		All	6w	3m ²	6m ²	1y ²	
Murmurs	Clinically innocent murmur		4w	Continue until <ul style="list-style-type: none"> Resolved, or Seen in JCC, or Referred to paed^s³ 			
Haemolytic disease	Exchange transfusion Positive DCT		6w	3m			
Hydronephrosis	Unilateral HN >10mm		4w				
HIV	See separate protocol		6w	3m	1y	18m	
Maternal thyroid disease	Hyperthyroidism Congenital hypothyroidism		2w ⁴				

¹ Normally in conjunction with community paediatrics at Seaside View CDC (or earlier if clinical concern)

² Refer to community paediatrics at Seaside View CDC if abnormal neurology or disability anticipated. Discharge from neonatal follow-up after handover of care.

³ Refer to consultant paediatrician after first appointment with JCC if ongoing cardiac follow-up required

⁴ Refer to Dr Kanumakala if ongoing follow-up required

See also protocol for neurodevelopmental follow-up of term babies born with apparent perinatal hypoxic ischaemic encephalopathy.

4. Specialist Medical Problems

For babies with specific medical problems, for example, anatomical abnormalities or syndromes follow-up may include referral to a Specialist Consultant Clinic.

Specialist Clinics:

- Clinical Genetics (Dr Mohammed, Geneticist, from Guy's Hospital)
- Cardiac and Echocardiography Clinics (Dr Miller)
- Endocrinology (Dr Kanumakala, RAH)
- Gastroenterology (Dr Butt, RAH)
- Respiratory (Dr Seddon, RAH)
- Surgical Clinic (Paediatric Surgeons, RAH)
- Urology (Mr Kalidasan, RAH)
- Plastic Surgery (Paediatric Plastic Surgeons, Queen Victoria Hospital, Lewes)
- Orthopaedics (Mr Turnbull, RAH)
- Ophthalmology (Mr McLeod/Mr Heath, Sussex Eye Hospital)

Such patients should be discussed with a consultant and referred in writing prior to discharge. If not admitted to the Unit a set of hospital notes should be generated by the postnatal ward clerk on level 12 and a NIPE referral generated.

Neurodevelopmental Follow-Up (Preterm)

This guideline refers to preterm infants **<30 weeks gestation and/or <1000g birth weight**.

At term (38-42 weeks' corrected age)

- Audiology screening prior to discharge
- Screening for retinopathy of prematurity (ROP guideline)
- Prechtl movement assessment prior to discharge (Brighton and PRH babies)
- Physiotherapy and/or speech and language therapy assessment
- May need early referral to local Child Developmental Clinic (CDC).

Neurodevelopmental follow-up should, at a minimum include 3, 6, 12 and 24 month checks.

Three, 6 and 12 month baby clinic checks are offered for Brighton and PRH booked babies. Other network babies should receive their first year developmental checks locally.

At 24 months corrected age all infants cared for on the TMBU in the first 24 hours of life and from the Sussex Network will be offered a 24 month Bayley III assessment.

At 3 months corrected age (Brighton and PRH babies only)

- Neurological examination (Hammersmith term neurology proforma)
- Repeat Prechtl movement assessment if there were concerns at term
- Refer to CDC, physiotherapy and speech and language therapy if concerns
- If no concerns review progress routinely in baby clinic at **6 months corrected age**.

At 12 months corrected age (Brighton and PRH babies only)

- Neurological examination (Hammersmith infant neurology proforma)
- Schedule of Growing Skills assessment
- Hand over neurodevelopmental follow-up to CDC or make a new referral if concerns.
- Review routinely at 24 months corrected age for a Bayley III assessment

At 24 months corrected age (all babies in Sussex Network)

- Bayley III assessment (may be undertaken at CDC for those Brighton babies already known to Seaside View)
- Health Status Questionnaire (TRPG / SEND proforma)
- Inform health care colleagues of findings, make new referrals as appropriate

Neurodevelopmental Follow-Up (Term HIE)

This guideline refers to **term infants** diagnosed as having **grade 2 or 3 hypoxic ischaemic encephalopathy**. Almost all will have received cooling therapy.

Day 1

- Neurological examination (further neurological assessments as appropriate)
- Assess and document aEEG findings

Day 7 to 10 or on recovery prior to discharge

- Neurological examination
- Audiology screening prior to discharge
- Cranial MRI
- Complete Cooling Register documentation
- Physiotherapy and/or speech therapy assessment as appropriate
- May need early referral to local Child Developmental Clinic (CDC).

Neurodevelopmental follow-up should, at a minimum include 3, 6, 12 and 24 month checks.

Three, 6 and 12 month baby clinic checks are offered for Brighton and PRH booked babies. Other network babies should receive their first year developmental checks locally.

At 24 months all infants from the Sussex Network that received cooling therapy on the TMBU will be offered a Bayley III assessment.

At 3 months (Brighton and PRH babies only)

- Neurological examination (Hammersmith term neurology proforma)
- Refer to CDC, physiotherapy and speech and language therapy if concerns
- If no concerns review progress routinely in baby clinic at **6 months**.

At 12 months (Brighton and PRH babies only)

- Neurological examination (Hammersmith infant neurology proforma)
- Schedule of Growing Skills assessment
- Hand over neurodevelopmental follow-up to CDC or make a new referral if concerns.
- Review routinely at 24 months corrected age for a Bayley III assessment

At 24 months corrected age (all babies in Sussex Network)

- Bayley III assessment (may be undertaken at CDC for those Brighton babies already known to Seaside View)
- Health Status Questionnaire (TRPG / SEND proforma)
- Complete Cooling Register documentation
- Inform health care colleagues of findings, make new referrals as appropriate

(Sept 2002 - PA, updated Jan 2005, Sept 2007, Oct 2011, review date Oct 2013)

Medical Follow-Up:

NIPE REFERRAL LETTERS WILL NEED TO BE GENERATED.

Low birthweight

All babies whose birthweight <2nd centile or less than 32 weeks' gestation are routinely followed up, initially in the Baby clinic (usually 6 weeks after discharge).

Birth asphyxia

Babies are not followed up on the basis of apgar scores alone but should be seen if they had asphyxia sufficient to produce neurological or behavioural abnormalities in the neonatal period. These babies should be followed up until at least one year of age to rule out significant motor problems.

Down Syndrome

Discuss with consultant. Bloods should be sent to Guy's for chromosome testing. Referral made to Helen Burley at the Seaside View CDC. Review in Baby Clinic if there are medical problems (e.g. heart defect).

Erb's Palsy

Discuss with consultant. Consider referral for physiotherapy and make initial outpatient appointment for 2-4 weeks to review progress. If the palsy hasn't resolved baby will need referral to Stanmore Orthopaedics for nerve transplant.

Hyperbilirubinaemia

Babies who have had an exchange transfusion should (i) have haemoglobin monitored after discharge, and be seen at 3 months in Baby Clinic, (ii) be referred for audiology.

Neonatal convulsions

All need follow-up - discuss with consultants.

Heart murmurs

Should be reviewed by Registrar. Four limb blood pressure and post ductal saturations should be done prior to discharge. Chest x-ray and ECG should be considered. Follow-up is dependent on clinical findings. Urgent referrals may be made to the Paediatric Cardiology Registrar at the Evelina Children's Hospital or Dr. Venugopalan (Paediatrician with an interest in Paediatric Cardiology, RAH). Non-urgent follow-up should be arranged in 2-4 weeks in Neonatal Outpatient Clinic at the RAH. All parents should be counselled at discharge of the potential for clinical deterioration and advised to seek help immediately. Sometimes it is possible to arrange echocardiography by one of the Consultant Neonatologists prior to discharge.

Cleft lip

See information in blue CLAPA file. This file contains up-to-date parent information, guidance for feeding and notification/referral forms. Referrals should be in the first instance to the lead specialist nurse: Sue Butcher on **01342 410210, ext 4212**. She is based at the Queen Victoria Hospital at East Grinstead. Following an initial visit from the nurse specialist team an appropriate appointment will be arranged with the surgical team led by Mr Boorman.

Genetic counselling will be offered to all parents who require it.

Teeth

Refer to Orthodontist.

Brachial plexus injuries

Should be seen by Registrar and discussed with Consultant prior to discharge. X-ray clavicle and upper limb and refer to Physiotherapist. Review in Baby Clinic at 4 weeks.

Head USS abnormalities

Follow-up should be discussed with Consultant if present in baby who would not otherwise be followed up. (See head USS abnormalities.)

Follow-up on other conditions should be discussed with Registrar or Consultant.

Surgical Problems:

Hydroceles

No surgical referral necessary, inform GP via NIPE referral letter.

Umbilical hernia

Reassure: most resolve spontaneously by a few years of age.

Para-umbilical hernia

Refer to surgeons prior to discharge.

Inguinal hernia

Refer to surgeons for review before discharge.

Undescended testes

- Unilateral – request GP for review at 4-6 weeks.
- Bilateral – requires registrar review and full investigation prior to discharge.

Hypospadias

Refer to surgeons. Advise against circumcision. Baby will usually be seen at a year of age.

Skin tags and accessory digits

Refer to Plastic Surgeons at Queen Victoria Hospital. Do NOT tie off skin tags with silk.

Spinal abnormalities

Blind ending, sacrococcygeal pits/sinuses below S2 are normal and do not need referral. If the sacral dimple is <2.5 cm from the anus and <5 mm from the midline then no further action or investigations are required, even if the base of it cannot be seen.

Ultrasound of the spine can be arranged with Paediatric Radiology for the following cases:

- If they are >25mm from anus or >5mm from the midline
- If there are other signs of spinal dysraphism (eg anorectal malformation or cloacal anomaly)
- If the dimple is discharging
- If there are neurological signs

This should be done as soon as possible after birth as the older the infant is the more difficult it is to visualise the spine.

Occult spinal dysraphism may be suggested by abnormalities of the skin and subcutaneous tissues overlying the spine. If in doubt, ask a consultant to review the baby in the following cases:

- Cutaneous dimples or sinuses above the level S2
Blind ending, sacrococcygeal pits below S2 are normal
- An abnormal collection of hair, a “tuft”
Slight hairiness may be a racial variation of normal
- Haemangiomas, pigmented macules, sacral aplasia or tags
- Subcutaneous masses including lipomas

Check for neurological signs in the lower limbs/patulous anal etc.

Midline defects

Midline spinal haemangiomas should have a spine x ray and USS and be referred if any abnormality.

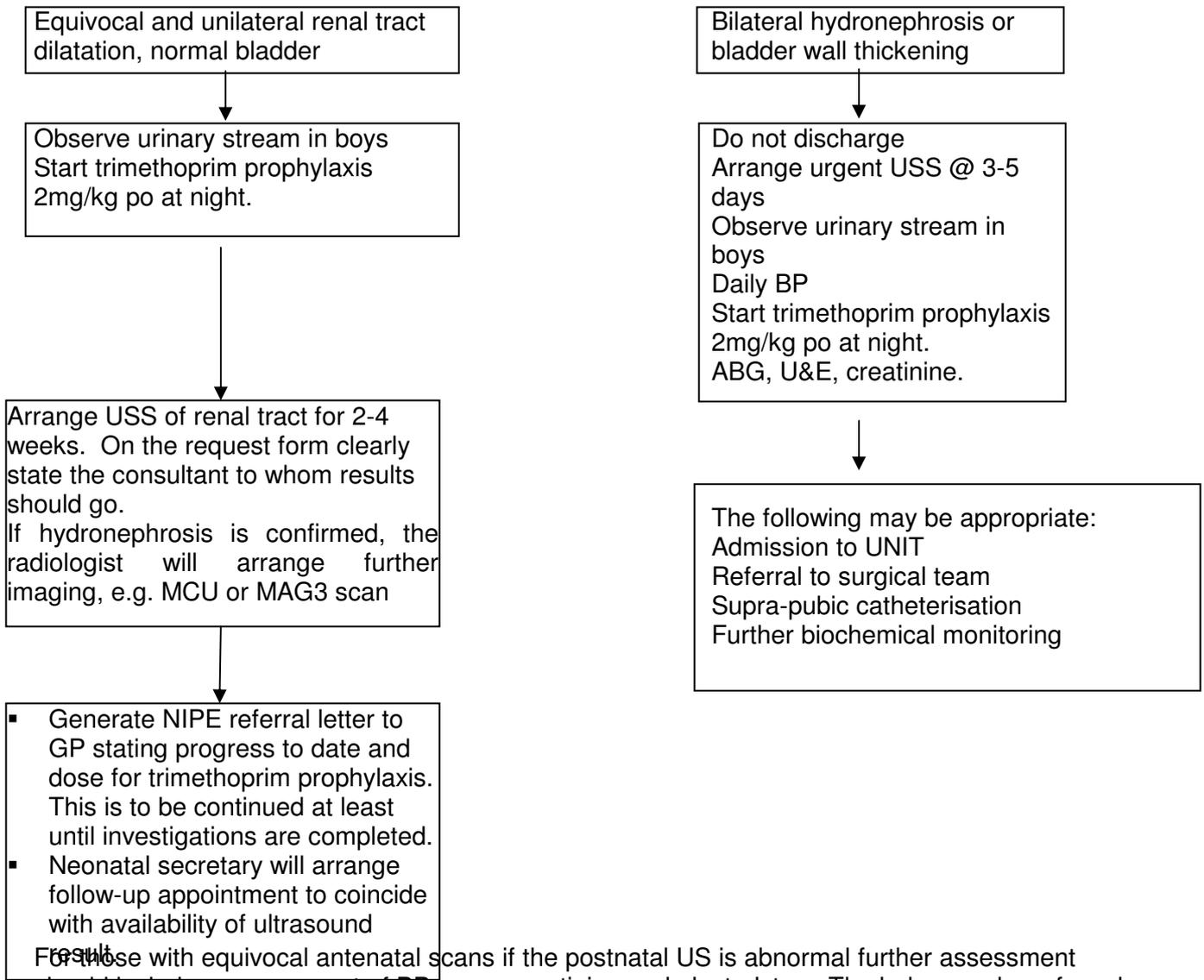
PARENTS MUST BE GIVEN AN EXPLANATION OF THE CONDITION AND REASON FOR REFERRAL BEFORE BABY IS DISCHARGED

Antenatally diagnosed hydronephrosis

Definition: Fetal renal pelvis AP-diameter >10mm on USS at 32-34 weeks gestation.

Following birth the SHO should perform a general examination for anomalies/dysmorphism including abdominal musculature and genitalia (hypospadias, testicular descent).

Review antenatal letters, there will usually be a plan already made for difficult cases. Discuss all cases of antenatal hydronephrosis with duty consultant for the postnatal ward.



For those with equivocal antenatal scans if the postnatal US is abnormal further assessment should include measurement of BP, urea, creatinine and electrolytes. The baby may be referred to Mr Kalidasan for further management as appropriate.

ORTHOPAEDIC FOLLOW-UP

HIPS

NIPE guidance (2010):

Irrespective of the clinical findings, an ultrasound examination of the hips should be performed if there is one or more of the following risk factors:

- 1) A first degree family history of hip problems in early life:
 - A first degree family history of hip problems in early life as defined by a positive response to the question, "Is there anyone in the baby's close family, i.e. mother, father, brother or sister, who has had a hip problem that started when they were a baby or young child that needed treatment with a splint, harness or operation?"
 - If the answer to this question is 'yes', an ultrasound examination should be arranged, unless DDH has been definitely excluded in that relative. If there is any doubt, an ultrasound examination should be performed.
- 2) A breech presentation at or after 36 completed weeks of pregnancy, irrespective of presentation at delivery or mode of delivery, or at delivery if this is earlier than 36 weeks.

In the case of a multiple birth, if one of the above is present all babies should have an ultrasound examination.

If there are no risk factors present, then only newborns with abnormal hip examination as defined below and after senior review should be referred:

- Hips should be classified as normal, dislocateable, or dislocated. Hips are considered unstable if they are either dislocated or dislocateable.
- Any newborn with suspicious or abnormal hip examination (including clicky hips) must be reviewed by a senior colleague (Paediatric Registrar or above). Senior review must be documented in the examination notes. A follow-up exam of the hips by the GP might be advisable (referral letter).
- Only unstable hips should be referred. They must be discussed with a Consultant Neonatologist before referral. It is not necessary to contact junior orthopaedic staff to review these babies.

Referral Process:

Miss Alexandra Smith (Paediatric Orthopaedic Surgeon) would like the following protocol for babies with risk factors or unstable hips:

- 1) Generate NIPE referral letter, ultrasound request (Radiology) and Orthopaedic Clinic request for abnormal hips
or NIPE referral letter and Orthopaedic One Stop Clinic request for positive family history
– Neonatal secretaries will send referrals off by internal mail or e-mail Miss Smith
 - 2) Request the L12 ward clerk to make a set of baby notes up
- If the hips are still unstable following orthopaedic review, then they will be put in a Pavlik harness. 90% of babies with unstable hips at 2 weeks of age treated in this way have normal hips by 9 months of age.

Feet

Talipes equinovarus

- All babies with a fixed deformity (the foot cannot be manipulated easily into the normal position) should be referred to Miss Alexandra Smith's team and the physiotherapists as soon as possible, so that treatment may be started immediately – ideally within 48 to 72 hours of birth.
- If there is doubt, or the feet can only be returned to the normal anatomical position with difficulty, physiotherapy may be indicated, and physiotherapy advice should be sought *prior to discharge*.
- Positional talipes, when the foot can be returned to the normal position, does not require treatment.

Calcaneovalgus deformity

These seldom need treatment but occasionally need reverse strapping. Ask the Physiotherapist to see if you think this may be necessary.

Miscellaneous:

Overlapping toes

- No treatment needed initially
- Strapping not helpful
- GP may refer at a later stage if felt to be a problem

Syndactyly

If just webbing of skin this is usually familial, of no functional significance and requires no treatment.

Extra digits

Refer to plastic surgeons

Do NOT tie off with silk - it is possible to tie off the wrong digit in this way and often leaves unsightly tags.

Retinopathy screening and eye follow-up

This is provided by Mr D. Heath and Miss V. Barrett

Please refer directly to the above named for any urgent or non-urgent abnormality other than ROP.

ROP Screening

Timing of first screening	
< 27 weeks gestation	30 - 31 weeks post menstrual age
27 - 32 weeks	4-5 weeks of age
> 32 weeks, < 1501g	4-5 weeks of age
Frequency of screening	
Every 2 weeks	
OR	
Weekly if	Vessels end in zone 1 or posterior zone 2 [or] Any plus or pre-plus disease [or] Any stage 3 disease in any zone

Audiology Screening

The incidence of congenital hearing impairment is 1-2/1000. Delayed diagnosis is associated with loss of valuable opportunities for auditory habilitation and speech development.

All newborn babies admitted to the Neonatal Unit for >48 hrs will be screened with Otoacoustic Emission (OAE) and automated auditory brainstem response (AABR) testing when they reach 35 weeks.

If screening is missed it is the task of the screening nurses to refer to the Audiology Department at Brighton.

Babies who are not admitted to the neonatal Unit will have OAE screening carried out by their health visitor.

Risk factors:

1. Family history of sensorineural hearing loss
2. Hyperbilirubinaemia requiring exchange transfusion
3. Dysmorphic syndrome associated with hearing loss
4. Congenital viral infection
5. Ventilation for more than a few days
6. Prolonged aminoglycoside therapy
7. Severe perinatal hypoxia
8. Abnormality of the ears
9. Serious visual abnormalities
10. BW < 1000gm
11. BW 1001-1500gm and significant hypoxia
12. Neonatal septicaemia or meningitis

Investigation of neonates diagnosed with severe/profound sensory neural hearing loss

Investigations which should be carried out on UNIT are those looking for congenitally acquired infection and, if possible, before 3 weeks of life (since later positive results can indicate postnatally acquired infection):

- Serology for CMV*, Rubella, Toxoplasma HSV*, and Treponema Pallidum.
- In the case of CMV, Lab can look for Avid IgG which indicates recently acquired infection.
- Urine, virus isolation of the above. CMV (DEAF test).
- Vesicles or other body fluids – virus isolation.

*Negative serology does not preclude infection since congenitally infected foetus has a delayed immunological response to the virus.

The maternal antenatal serological specimen if possible should be retrieved to allow comparative pre and post natal serology.

There are clear pathways in place for management of the deaf child from diagnosis. Janine Blundell, at the Seaside View CDC, will review infants with the multi-disciplinary team. Further investigations into aetiology and genetic counselling are then pursued.

NB An ECG to look for prolonged QT interval is difficult to interpret in the neonate and therefore this is not a meaningful investigation to carry out in early life to exclude Jervell Lange Nielsen Syndrome.