REFERRAL PATHWAY FOR NEWBORNS WITH CONGENITAL HAND DIFFERENCES

Congenital hand differences (CHD) are relatively common, about 1:600. Although the majority of CHDs are considered relatively minor, there is always a certain degree of parental anxiety and apprehension about the child's future. This is especially so if abnormalities were not detected antenatally.

There are two main issues concerning any CHD in the immediate postnatal period: function and appearance (cosmesis). Cosmesis is usually the predominant source of anxiety initially as functional developments (and handicaps) are not immediately apparent. Cosmetic concerns are also more pressing and parents may not feel equipped to answer questions from relatives and friends or respond to comments about their child's hand difference. There will be many questions and concerns that the parents have during this period.

The aim of this referral pathway is to help the health professional looking after the child deal with some of these concerns, and to make the appropriate referral, to the right team and at the right time. It is not meant to be exhaustive but all non-emergency questions can be directed to Mr Wee L Lam, Consultant Plastic and Hand Surgeon at RHSC, or Orla Duncan, Congenital Hand Psychosocial Practitioner at RHSC. Emergency referrals (e.g., compromised limbs) must be referred to the on-call Plastic Surgery team.

IMMEDIATELY AFTER BIRTH

There is a wide range of CHD, ranging from the simple pedunculated polydactyly, to a complete absence of the hand or upper limb. The first thing to decide is whether the child needs to be seen as an emergency.

Emergencies:

The following are examples of emergency referrals (very rare):

- A distally compromised limb secondary to a constriction band: There is a tight band around the upper (or lower limbs) resulting in distal swelling, with or without colour change (purple, black or white).

- Neonatal compartment syndrome: Usually characterised by an ischaemic or atrophied looking limb with open wounds.

All other CHDs should be referred by email to Ms Pauline McGee/Ms Lucie Wright, Consultant Plastic and Hand Surgeon at RHSC, Tel: 0131 536 0978 (Sandra Stewart, secretary). When making a referral for a simple polydactyly, it is important to describe the condition as accurately as possible.
Emails:
pauline.mcgee@nhs.scot
lucie.wright@nhs.scot

Polydactyly:

For example:

“A simple polydactyly on the ulnar border of the hand (post-axial polydactyly) connected by a simple, pedunculated stalk measuring 1-2 mm.”

VS
“A polydactyly on the ulnar border of the hand, that seems to be connected via a broad base measuring at least 5mm, and appears to contain bone and joints within the connection.”

The former can be excised under local anaesthesia, but is best done if the child is under 3 months old. Therefore, he or she can potentially be listed directly for theatre, without going through an OPD and delaying the time period from birth to surgery. The latter requires a general anaesthesia and can wait until the child is older. A routine referral for an OPD appointment is therefore appropriate (see below).

THE CONGENITAL HAND CLINIC:

Except for the conditions listed above, most conditions can wait to be seen until the child is around 3 months old. The time of referral to the time the child is seen is usually around this period (3 months).

The medical or nursing staff looking after the Parents/ Carers and child at this stage can then reassure them that a referral has been made and they would be seen within this time. However, there may be a number of parents who remained distressed and would like an earlier referral or to talk to someone on the CHD team.

Below is a simple classification which may help the health staff when deciding who is suitable for earlier referral:

- Type 1 - Correction possible to normal, e.g., polydactyly, most patients with extra fingers or toes
- Type 2 - Correction possible to near normal, e.g., syndactyly (webbed fingers)
- Type 3 - Correction possible but may always look different e.g., Abnormally shaped, missing or severely shortened/smaller digits, arthrogryposis
- Type 4 - Correction not possible, e.g., missing hand or forearm

We recommend referring babies with ***types 3 or 4*** to Orla Duncan, CHD (Psychosocial Practitioner at orla.duncan@nhslothian.scot.nhs.uk, or Tel: 07711017549, or at least offer these parents a referral before three months. Referrals to Orla can also be made for types 1 and 2 if they are distressed and anxious about the child’s hand. Orla can come and see these parents while they are still in hospital or visit at home.

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WHAT IS LIKELY TO HAPPEN IN THE FUTURE

It may be useful to give the parents a timeline of what is likely to happen in the future for the child. Please inform them that:

- The child will be treated within a multi-disciplinary team where any other paediatric concerns are addressed, and any other investigations carried out
- The child will be seen in a multi-disciplinary OPD at three months consisting of the surgeon, the therapist, and the Psychosocial Practitioner
- The family and child may be offered an appointment to see a geneticist for family counselling and to try and find out further the cause of the CHD
- Surgery may not always happen
- Surgery may not always be possible
- The majority of surgery will be carried out when the child is around one year of age, mainly for safety concerns with GA

MORE INFORMATION…

For more information or any other queries, please feel free to email addresses as above.

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