**CLINICAL ETHICS SERVICE**

**REFERRAL FORM 2**

**DISORDER OF SEX DEVELOPMENT (DSD)**

**CHECKLIST**

Patients with a DSD, for whom surgery is proposed, are normally referred for a Clinical Ethics meeting, as part of the standard pathway. Use the Referral Form 2 attached for all DSD referrals.

Infants with CAH **do not** need to be referred to clinical ethics, if the following criteria are met, and there are none of the special factors listed below.

**Infant with CAH - Criteria for proceeding without clinical ethics meeting**

If all the following criteria are met, there is **no need** to refer the patient to clinical ethics:

1. Child is under 12 months of age
2. Child has uncomplicated CAH, no other medical conditions
3. The genital appearance is Prader Stage 3 or above ie the stage of virilisation where international guidelines permit surgical reduction
4. Parents have been provided with standard written information (which explains options of surgery in infancy vs later in childhood, pros and cons of each; timing of surgery in infancy, and option to wait 1-2 months to see if clitoral size reduces, pros and cons of this; option to delay surgery to separate labia until childhood, but have clitoral reduction in infancy, and pros and cons of each)
5. Parents have chosen feminising surgery (clitoral reduction and/or labioplasty) in infancy

Only refer for clinical ethics meeting if **any one** of these apply:

* Parents disagree with each other about surgery
* Clinicians have different views about appropriateness of surgery
* Any member of treating team has any other concerns.

Use the Referral Form 2 attached for these CAH cases.

**CLINICAL ETHICS SERVICE**

**REFERRAL FORM 2**

**DISORDER OF SEX DEVELOPMENT (DSD)**

All patients with a DSD, for whom a surgical procedure is proposed, are normally referred for clinical ethics review, as part of standard pathway. For infants with CAH, in ethically straightforward circumstances, referral to clinical ethics is not needed. Please use Checklist above.

1. **Child Name, DoB and UR:**
2. **Date of referral:** / /
3. **Treating clinician and contact person *(if different):***
4. **Diagnosis *(indicate uncertainty, if relevant*):**
5. **Brief history:** 
   1. **Medical**
   2. **Social/family, including cultural or religious aspects that are relevant**
   3. **Other family members *(if relevant)***
6. **Brief summary of the current situation:**
7. **Brief overview of discussions held with:**
   1. **Parents**
   2. **child/young person *(if relevant)***
   3. **other family members *(if relevant)***
8. **Proposed gender of rearing and rationale - specifying factors on which the decision was based *(if relevant):***
9. **Proposed management plan with rationale (specifying factors on which the decision was based), including:**
   1. **Any proposed surgery, and rationale**
   2. **Any proposed medication, and rationale**
   3. **Proposed psychosocial support and follow-up for family**
10. **Parents’ and child’s views on proposed gender of rearing *(if relevant)* and management plan:**
11. **Any particular ethical questions concerns or issues identified by treating team:**
12. **Timeline: how soon is Clinical Ethics response needed?**

Please indicate any preferred days and timeslots.

1. **List key medical, nursing and allied health from treating team needed at meeting:**

**Please email referrals to:**

Clinical Ethicist, Lynn Gillam, at [lynn.gillam@rch.org,au](mailto:lynn.gillam@rch.org,au), and

Cc to:

Team Leader, Jenny Hynson, at [jenny.hynson@rch.org.au](mailto:jenny.hynson@rch.org.au) and

Ethics Project Officer, Karen Fellows, at [karen.fellows@rch.org.au](mailto:karen.fellows@rch.org.au)