

**Scottish Paediatric & Adult Infection & Immunology Network (SPAIIN)**

Pathway for Assessment and Management of Children and Young People Requiring Haematopoietic Stem Cell Transplantation for Primary Immunodeficiency

**Initial Assessment**

* Patient is discussed with/referred to a SPAIIN paediatric immunologist.
* Level of urgency established:
* Urgent cases (e.g. SCIDS) is assessed by a SPAIIN paediatric immunologist and discussed with the three paediatric immunologists in Scotland in conjunction with the Scottish national paediatric bone marrow transplantation service in Glasgow, with input from a Newcastle paediatric immunologist.
* Other cases will be invited to the SPAIIN network clinic for further assessment.
* If transplant deemed appropriate, on the basis of this assessment i.e. underlying condition, co morbid conditions/complications or organ compromise, potential source/match of stem cells and perceived difficulties of transplantation then the location of the transplant will be determined i.e.
* Standard risk transplantation for PID will take place in Glasgow.
* Higher risk transplantation for PID will take place in Newcastle.
* If a consensus regarding risk/location of transplantation cannot be achieved within the group of clinicians then outside expert advice will be sought.
* If a PID transplant is undertaken in Glasgow then further support will be sought from the Newcastle PID service in their planning and throughout the transplantation process if problems arise.
* If a transplant is deemed ‘higher risk’ then the patient will be referred to the Newcastle service.

**Referral for Transplantation**

* Once the site of transplant has been determined, a formal referral will be made.
* A detailed written summary will be sent to the lead consultant for the referral transplant service, with copies to all those involved in the discussion as above.

* Co-ordination of the work up for transplant will be the responsibility of the transplant team. However, the referring team may be involved in aspects of this work up in discussion with the transplant team, particularly if the child is resident at a distance from the transplant centre.
* Responsibility for overall patient care will remain with the referring team until either the child is admitted to RHC Glasgow for the procedure or transferred to Newcastle.

**HSCT – First 100 Days**

The transplant team will have responsibility for patient care:-

**Patients transplanted in Glasgow:**

* Inpatients will be reviewed by the immunology team at least weekly in discussion with the transplant team, and may give advice on a “consult” basis.
* Support may be offered by members of the immunology team as appropriate, particularly in families who have long-standing relationships with the team.
* The Glasgow immunology team will update the referring immunologist/link clinician if patient not Glasgow based weekly by email or telephone.
* If patient not Glasgow based, arrangements will be made for teleconferencing to involve the local clinicians in the event of significant discussions regarding the patient being required.

**Patients transplanted in Newcastle:**

* A member of the Newcastle transplant team will be identified as being responsible for communication with a nominated SPAIIN clinician.
* The Newcastle clinician will update the SPAIIN clinician weekly, by email or telephone, and at network clinics.
* Arrangements will be made for teleconferencing to involve SPAIIN and local/link clinicians in the event of significant discussions regarding the patient being required.

**Post 100 Days**

* On or around 100 days, a multi-disciplinary conference will be arranged, using teleconferencing if necessary, involving the transplant team, SPAIIN immunologist(s) and local/link clinicians.
* At this conference, arrangements for ongoing follow up and care will be determined, based on individual circumstances, nature of any complications experience during transplant, and resources and expertise available to the local team.
* Responsibility for care will be resumed by a SPAIIN immunologist unless:
* The patient is still an inpatient in Newcastle, in which case responsibility for care will be transferred at the time of discharge.
* The patient has major transplant-related sequelae requiring ongoing management for which the necessary expertise lies with the transplant team.
* Other circumstances agreed after multi-disciplinary discussions.
* A close ongoing relationship between the transplant team and the immunology team will be maintained:
* Patients transplanted in Newcastle will be reviewed in the SPAIIN network clinics, and the SPAIIN clinician will arrange review as required and communicate at least monthly with the nominated Newcastle clinician until one year post transplant. Any proposal to review patients in Newcastle following discharge will be discussed and agreed by SPAIIN and Newcastle clinicians.
* In the event of a patient returning to Newcastle for review, an initial summary of the visit, including investigation results will be sent to the responsible SPAIIN immunologist within two weeks (either by post or email).
* Patients transplanted in Glasgow will be reviewed in the Glasgow Stem Cell Transplant clinic attended jointly by the transplant team and paediatric immunologist.
* Long term follow up will be conducted according to the Newcastle protocol, and data collected will be shared with Newcastle, and the appropriate registries.

**Transition to Adult Care:**

* Before the age of 16 a lead clinician will be identified to undertake long term follow up in adult services.
* Timing of transition will be agreed between the young person and the involved clinicians.
* Young people with no residual identified co-morbidity will transition to care of adult immunology service for ongoing annual review.
* Young people with transplant related late effects will in addition be referred to the adult stem cell transplant team.
* A joint review will be planned before completion of transfer to adult services.
* In patients with complex or multiple co-morbidities, involving the input of a number of paediatric specialities, an MDT will be arranged between those involved within paediatric services and those identified within adult services to undertake ongoing care.
* For patients transplanted in Newcastle, correspondence from annual review and other relevant episodes will be copied to the Newcastle clinicians. This will be the responsibility of the lead clinician.