



## PEDIATRIC BLOOD AND MARROW TRANSPLANT PROGRAM

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Policy for Patient and Family Education

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# **PBMT-GEN-036**

## **POLICY FOR PATIENT AND FAMILY EDUCATION**

### **1 PURPOSE**

- 1.1 To describe the methods used to educate the patient, family, and/or legally authorized representative(s) (LARs) about hematopoietic stem cell transplantation or when applicable, cellular therapy or gene therapy.

### **2 INTRODUCTION**

- 2.1 Hematopoietic stem cell transplantation is a complex process. Therefore, patients and their families, and/or legally authorized representative(s) require education regarding the risks and benefits of transplantation in order to make an informed decision to proceed. The education process begins with the initial contact with the patient, family, or legally authorized representative(s) by either the physician or Clinical Service Nurse (CSN) nurse clinician and extends through the period of hospitalization, post-discharge outpatient care, and long-term follow-up for late effects.
- 2.2 This procedure is used to educate the transplant patient, family and/or legally authorized representative(s) about hematopoietic stem cell transplantation or, when applicable, for cellular therapy.

### **3 SCOPE AND RESPONSIBILITIES**

- 3.1 Physicians, Clinical Service Nurse (CSN), nurses, advanced practice providers (APP), social workers, child life specialists, discharge planners, home health providers and pharmacists are responsible for the contents and application of this procedure.

### **4 DEFINITIONS/ACRONYMS**

- 4.1 CT Cellular Therapy
- 4.2 CSN Clinical Service Nurse
- 4.3 LAR Legally Authorized Representative
- 4.4 PJP Pneumocystis Jiroveci Pneumonia
- 4.5 PTCT Pediatric Transplant and Cellular Therapy
- 4.6 SOS Sinusoidal Obstruction Syndrome
- 4.7 VOD Veno-occlusive Disease

### **5 MATERIALS**

- 5.1 Parent Handbook
- 5.2 Road to Transplant Flip Chart
- 5.3 Patient Transplant Roadmap
- 5.4 Chemotherapy and Medication Fact Sheets

- 5.5 Informed consent(s)
- 5.6 Discharge roadmap and medication administration sheets
- 5.7 Letters home to referring physicians, copied to parents/caretakers
- 5.8 Vaccination protocol(s)
- 5.9 Management of antibiotic prophylaxis for fever, dental work, surgical procedures
- 5.10 NC Workup Checklist (see related procedure: PBMT-GEN-011 *NC Work-up Checklist*)

## **6 EQUIPMENT**

- 6.1 N/A

## **7 SAFETY**

- 7.1 N/A

## **8 PROCEDURE**

- 8.1 Documentation of consultation/teaching/education mentioned in this procedure regardless of location (either inpatient and/or outpatient) will be completed in the patient's electronic medical record and will include learner outcomes.
- 8.2 Some roles are unique to each staff discipline and area of expertise, but preparation/education of the family unit is a collaborative task across the team.
- 8.3 Following initial referral, review by the clinical team and decision to evaluate the patient for transplant:
  - 8.3.1 Clinical Service Nurse (CSN):
    - 8.3.1.1 Contacts the patient, family, and/or legally authorized representative(s) and educates about the program utilizing PBMT-GEN-011 *NC Work-up Checklist*.
    - 8.3.1.2 Forwards patient's insurance information to the program's insurance coordinators.
    - 8.3.1.3 Sends introductory materials to the family.
    - 8.3.1.4 Develops initial schedule for the workup.
    - 8.3.1.5 Documents education in the electronic medical record.
  - 8.3.2 Social Worker:
    - 8.3.2.1 Performs an assessment in person, or virtual when required, during the workup process unless specific needs are identified in advance.
      - 8.3.2.1.1 Psychosocial assessments are performed on all patients as part of the workup process.
    - 8.3.2.2 Informs hospital school teachers of patient arrival to the program.

- 8.3.3 Family Support Team:
  - 8.3.3.1 Provides educational materials about support programs (e.g., Best Buddies, patient, sibling and parent support groups, etc.)
- 8.3.4 Child Life Specialist:
  - 8.3.4.1 Helps patients cope with the transplant experience through adapted and medical play, education and developmentally appropriate interventions.
- 8.3.5 Lodging Coordinator:
  - 8.3.5.1 Provides materials for local housing options.
- 8.3.6 School Teachers:
  - 8.3.6.1 Liaison with the patient's regular school system and teachers to develop a curriculum and teaching plan at Duke.
- 8.4 The physician consults with patient, family, and/or legally authorized representative(s) to discuss risks, benefits and mechanics of the pre-transplant work-up, line placement, cytoreduction, donor identification and characteristics, transplantation procedure, post-transplant care both in the hospital, in Durham and at home and in anticipated late effects. All families are informed of the high risk of future infertility. Patients in or beyond adolescence are informed of options for fertility preservation. The physician records consultation in the electronic medical record.
- 8.5 The Clinical Service Nurse (CSN) conducts formal education sessions with patient, family, and/or legally authorized representative(s) using program specific educational tools (tour of the facility, Road to Transplant, Parent Handbook, Patient Transplant Roadmap, Chemotherapy and Medication Fact Sheets). Education to include:
  - 8.5.1 Central venous line placement and care
  - 8.5.2 Mouth Care
  - 8.5.3 Isolation
  - 8.5.4 Infection Precautions
  - 8.5.5 Process review of Donor screening
  - 8.5.6 Preparative Regimen for Conditioning
  - 8.5.7 Prophylaxis meds for the following:
    - Graft Versus Host Disease (GVHD)
    - Viral infections
    - Fungal infections
    - Veno-Occlusive Disease (VOD) / Sinusoidal Obstruction Syndrome (SOS)
    - Pneumocystis jiroveci Pneumonia (PJP)

- 8.5.8 Growth Colony Stimulating Factor (GCSF)
- 8.5.9 Intravenous Immune Globulin (IVIG)
- 8.5.10 Transfusions
- 8.5.11 Total Parenteral Nutrition (TPN)
- 8.5.12 Pain Management
- 8.5.13 Parental Blood Draws
- 8.5.14 Apheresis (if applicable; education usually provided prior to transplant workup)
- 8.5.15 Donor Selection
- 8.5.16 Outpatient Care Expectations
- 8.5.17 Sun Precautions
- 8.5.18 Skin Care
- 8.5.19 Dietary Restrictions
- 8.5.20 Possible need for intensive care for ventilatory support and/or blood pressure support
- 8.6 The physician consults with the patient, family and/or legally authorized representative(s) to review test results and review donor selection.
- 8.7 The CSN meets with the patient, family, and/or legally authorized representative(s) for a pre-consenting session to review consent, review patient roadmap, and to formulate questions for consenting session with physician.
- 8.8 The physician and CSN will meet with the patient and family to review and sign consent(s) for transplant. The physician will complete documentation of the patient meeting in the electronic medical record. Consents are electronically scanned to patient's electronic medical record. Alternately, if needed, records may be sent to medical records to be scanned into the patient's electronic medical record. Copies of each consent(s) are given to the patient, family, or legally authorized representative(s).
- 8.9 Patient education continues upon admission to the inpatient unit by physicians, staff nurses, advanced practice providers, discharge planner, dietitian, and pharmacist.
  - 8.9.1 The dedicated pharmacist:
    - 8.9.1.1 Rounds with the inpatient team and attends the weekly patient management meeting.
    - 8.9.1.2 Provides ongoing education around medications and toxicities occurring in the transplant and post-transplant period.
    - 8.9.1.3 Is available for additional education sessions as needed.
  - 8.9.2 The dietitian:
    - 8.9.2.1 Rounds with the inpatient team.

- 8.9.2.2 Provides ongoing education and is available for consultation throughout the continuum of care.
- 8.9.3 The dedicated Discharge Planner:
  - 8.9.3.1 Holds discharge education sessions on the clinical unit. This education is reinforced by the staff nurses.
  - 8.9.3.2 Documents teaching and learner outcomes in patient's electronic medical record and on the appropriate homecare teaching sheet.
- 8.9.4 Advanced Practice Providers (APP):
  - 8.9.4.1 Provide ongoing education during inpatient rounds
- 8.10 Prior to discharge back to the patient's home, under the care of the referring physician, facilitates return home. If the referring physician does not have access to the electronic medical record, or if requested by the referring team, a detailed clinic note, or summary of care is written and provided to all referring providers. If they do not have access to MyChart, this information may also be provided to the patient, family, or legally authorized representative(s) to keep as a reference for the plan for ongoing care.
- 8.11 Upon discharge from the inpatient unit, education continues in the outpatient clinic setting by the medical team – including nurses, APPs, and physicians.
  - 8.11.1 Following scheduled post-transplant evaluations, ongoing care plans are made and detailed in communication to the referring provider. The plan includes: future long-term follow-up, medication weans, return to school and extra-curricular activities, immunizations, organ function follow-up (e.g., dental, ophthalmologic, etc.).

## 9 RELATED DOCUMENTS/FORMS

- 9.1 PBMT-GEN-011 NC Work-up Checklist

## 10 REFERENCES

- 10.1 N/A

## 11 REVISION HISTORY

Revision No.	Author	Description of Change(s)
08	<u>MC author:</u> Sally McCollum  <u>SME:</u> Clinical Service Nurse Team/ Erika Goeckermann	<ul style="list-style-type: none"> <li>- Throughout document:               <ul style="list-style-type: none"> <li>o Nurse Coordinator (NC) language adjusted to Clinical Service Nurse (CSN) to align with currently used terminology.</li> <li>o Child Life Specialist Role Included</li> </ul> </li> <li>- Section 8.3: allowance for virtual assessments and inclusion of psychosocial assessments as part of workup.</li> </ul>

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