**Document Information**

<table>
<thead>
<tr>
<th>Revision:</th>
<th>06</th>
<th>Vault:</th>
<th>PBMT-General-rel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Status:</td>
<td>Release</td>
<td>Document Type:</td>
<td>PBMT</td>
</tr>
</tbody>
</table>

**Date Information**

<table>
<thead>
<tr>
<th>Creation Date:</th>
<th>28 Jan 2021</th>
<th>Release Date:</th>
<th>17 Feb 2021</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effective Date:</td>
<td>17 Feb 2021</td>
<td>Expiration Date:</td>
<td></td>
</tr>
</tbody>
</table>

**Control Information**

<table>
<thead>
<tr>
<th>Author:</th>
<th>MOORE171</th>
<th>Owner:</th>
<th>MOORE171</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous Number:</td>
<td>PBMT-GEN-036 Rev 05</td>
<td>Change Number:</td>
<td>PBMT-CCR-318</td>
</tr>
</tbody>
</table>
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 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, nurse clinicians, nurses, advanced practice providers, social workers, discharge planners, home health providers and pharmacists are responsible for carrying out this procedure.

4 DEFINITIONS/ACRONYMS

4.1 CT Cellular Therapy
4.2 LAR Legally Authorized Representative
4.3 NC Nurse Clinician
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 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 Nurse Clinician (NC):
  8.3.1.1 Contacts the patient, family, and/or legally authorized representative(s) and educates about the PBMT program utilizing PBMT-GEN-011 NC Work-up Checklist.
  8.3.1.2 Sends introductory materials to the family.
  8.3.1.3 Develops initial schedule for the workup.
  8.3.1.4 Documents education in the electronic medical record.

8.3.2 Social Worker:
  8.3.2.1 Performs an assessment in person during the workup process unless specific needs are identified in advance.
  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 Housing Coordinator:
  8.3.4.1 Provides materials for local housing options.
8.3.5 School teachers:

8.3.5.1 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 NC 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 Roadmap, Chemotherapy and Medication Fact Sheet). Education to include:

8.5.1 Central venous line placement/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 NC 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 NC meet with 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 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:

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 MDs, as well as, the patient, family, or legally authorized representative(s), if they do not have access to MyChart, 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 a communication to the referring MD. 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

<table>
<thead>
<tr>
<th>Revision No.</th>
<th>Author</th>
<th>Description of Change(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>06</td>
<td>Sally McCollum</td>
<td>Language for BMT updated throughout to reflect HSCT and CT.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Section 8.2 added to reflect collaboration of the team.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Section 8.4 updated to include risk of infertility.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Section 8.10 updated to reflection provisions to referring providers.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Section 8.11 updated to reflect provisions for ongoing and long term care.</td>
</tr>
</tbody>
</table>
Signature Manifest

**Document Number:** PBMT-GEN-036  
**Title:** Policy for Patient and Family Education  
**Effective Date:** 17 Feb 2021

All dates and times are in Eastern Time.

**PBMT-GEN-036 Policy for Patient and Family Education**

### Author

<table>
<thead>
<tr>
<th>Name/Signature</th>
<th>Title</th>
<th>Date</th>
<th>Meaning/Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sally McCollum (MOORE171)</td>
<td></td>
<td>28 Jan 2021, 11:25:54 AM</td>
<td>Approved</td>
</tr>
</tbody>
</table>

### Medical Director

<table>
<thead>
<tr>
<th>Name/Signature</th>
<th>Title</th>
<th>Date</th>
<th>Meaning/Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joanne Kurtzberg (KURTZ001)</td>
<td></td>
<td>28 Jan 2021, 12:21:39 PM</td>
<td>Approved</td>
</tr>
</tbody>
</table>

### Quality

<table>
<thead>
<tr>
<th>Name/Signature</th>
<th>Title</th>
<th>Date</th>
<th>Meaning/Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bing Shen (BS76)</td>
<td></td>
<td>04 Feb 2021, 11:13:10 AM</td>
<td>Approved</td>
</tr>
</tbody>
</table>

### Document Release

<table>
<thead>
<tr>
<th>Name/Signature</th>
<th>Title</th>
<th>Date</th>
<th>Meaning/Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>Betsy Jordan (BJ42)</td>
<td></td>
<td>08 Feb 2021, 10:42:35 AM</td>
<td>Approved</td>
</tr>
</tbody>
</table>