

## **Providing Comprehensive Care to Patients with Epidermolysis Bullosa in the Perioperative Environment**

Team Leader: Emily Theis BSN RN

University of Minnesota Medical Center & Masonic Children's Hospital, Minneapolis, Minnesota

Team Members: Mary Briggs BAN RN CAPA, Gretchen Lilja BSN RN, Sarah Preusser MS PA-C, Elena Zupfer MD

**Background Information:** The University of Minnesota Medical Center and Masonic Children's Hospital EB Center offers comprehensive multidisciplinary care to children with Epidermolysis Bullosa (EB). This is the only center in the United States to offer Bone Marrow Transplantation (BMT) as a treatment for EB. To determine candidacy, these patients come to the Operating Room to have their dressings fully removed, labs drawn, photographs taken and skin biopsies collected under general anesthesia. The child is transported to PACU and remains under sedation while dressings are reapplied, often a 2-3 hour process. Since these patients are at high risk for severe blistering skin injuries, it was evident that modifications to equipment, practice changes, and staff education needed to occur to keep them safe during critical times in Perioperative Services when their usual expert care provider, often a parent, is not present.

### **Objectives of Project:**

- Design supplies and education to ensure that all disciplines and departments are equipped to care for the unique needs of the EB patient.
- Develop a mechanism to alert any provider who may come in contact with the patient in Perioperative Services that this patient is at high risk for injury.

### **Process of Implementation:**

- Identify an individual in each department or service line that would serve as the "EB Champion." Provide education to all staff that may provide direct patient care.
- Creation of the EB STOP Sign visual tool.
- Ongoing work with a product innovator to develop equipment for the Perioperative environment that is both safe for EB patients' skin and functionally allows for safe monitoring of the patient.

### **Statement of Successful Practice:**

- Demonstrate commitment to being a center of excellence for the EB patient, with resource support to meet the goal of skin injury prevention.

### **Implications for Advancing the Practice of Perianesthesia Nursing:**

- Multidisciplinary collaboration supported by leadership and implemented by anesthesia and nursing staff allows these patients at high risk for skin injury to be cared for in the safest way possible. Perianesthesia nurses provide critical elements of the care required to provide comprehensive treatment aimed at improving the quality of life for children living with EB.