



6th International Conference on Clinical Ethics Consultation

May 11-14, 2010 ♦ Portland Art Museum ♦ Portland, Oregon, USA
www.ethics2010.org



Abstract Submission Form

Please contact John Tuohey at ethics@providence.org with any questions.

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Additional panelists, if any (up to three):

Name: _____

Title/Degree: _____

Institution: _____

Country: _____

Name: _____

Title/Degree: _____

Institution: _____

Country: _____

Name: _____

Title/Degree: _____

Institution: _____

Country: _____

Proposed Session Title: Withdrawing of Medically Provided Fluid and Nutrition in a Patient with Epidermolysis Bullosa

Describe topic or case to be discussed up to 300 words:

JP is 4 week old male who had multiple bullous skin lesions at birth. Biopsy revealed recessive epidermolysis bullosa simplex—muscular dystrophy (EBS-MD). Initially, JP tolerated oral feeding with supplementary intravenous fluids, but by two weeks of life he began developing painful oral ulcers, and

stopped taking oral feeds. He required total intravenous nutritional support and ongoing pain control, especially for daily debridement and dressing changes of the skin lesions, which now involved 50% of his skin. In light of his inability to take oral nutrition, a gastrostomy tube (G-tube) was recommended. JP's parents expressed concerns about the morbidity of this procedure; including need for intubation during the procedure potentially resulting in tracheal trauma and subsequent tracheostomy and impaired gastrostomy wound healing secondary to EBS. In light of JP's overall prognosis with EBS-MD, including an expected difficult and painful clinical course, they refused to consent to a G-tube. Believing medical intervention would only prolong JP's dying process, they wished to withdraw medically provided nutrition and hydration. The consulting dermatologist was concerned that although there is very little published literature about this subtype, this would not be practicing standard of care for most subtypes of EBS.

Describe briefly each proposed panelist's position to be offered (up to 300 words):

Objectives:

1—Explore how “standard of care” is determined in a rare disorder.

2--Discuss the development of the “best” treatment plan for the patient with a rare disorder.

3—Review the important participants in determining treatment decisions for pediatric patients with rare disorders.

Are you planning to or will you be willing to submit a poster along with your panel?

Yes No