**Supplementary Document S1: Family Meeting Preparation Slides**

**Family Meeting Prep**   
(to be facilitated by a nurse or social worker)

1. **Meeting Basics & Communication Preferences**

* **Which type of meeting is this?** 
  1. an update after prolonged hospitalization (review of the child’s condition)
  2. giving serious news (new info about the child’s condition)
  3. discussing conflicting/confusing information (discussion to resolve conflicting information)
  4. discussing upcoming discharge
  5. supporting parental decision-making
* **Family’s Communication Preferences for**:
  1. How much info? (Detail vs. Big Picture)
  2. How do they want to receive info? (Verbal or written)
  3. Do they want a recommendation from the team? (or make their own decision)
  4. Anything else?

1. **Agenda for the family meeting**

* **What agenda items does the team want to discuss?** 
  + What EXACT words would we use?
* **What agenda items does the family want to discuss?**
  + “What concerns and questions do you have?”

1. **When the family expresses a negative emotion**

e.g., “I can’t believe all he’s had to go through” respond with empathy (**NURSE** statements)

* “This is really overwhelming”
* “I can’t imagine what you’re going through”
* “It’s clear how much you love your child”
* “You’ve been an amazing advocate”
* “We are here with you in this difficult time.”

1. **Participants and Roles**

* **Who does the family want present in the meeting?**
* **Anyone we need to contact before the meeting?**
* **Which role will everyone perform?**
  + **Facilitator:** Makes sure the meeting stays on track and that all relevant team members and family members are heard from. It’s usually better if this isn’t the same person providing most of the information.
  + **Information Giver:** Who will provide the main points for the agenda items? It may be different people for different agenda items.
  + **Documenter**: It helps the family to be able to review and retain the information after the meeting is over. Based on the agenda we just discussed, you will fill out the Family meeting summary worksheet during the meeting.
  + **Emotional Support Coordinator**: In charge of monitoring the emotions in the room.