Advocating for Yourself and/or Your Child

Beth Gore
March 26, 2010
Age 9 Months
May 2010 1st Hospitalization
June 26, 2010
1st Birthday

Dec 25, 2010
Christmas
Merosin Deficient Congenital Muscular Dystrophy

- Pulmonary weakness
- Progressive
- Non Ambulatory
- Average lifespan 11
- Manny severe on the scale
• Missing Diagnosis ... Merosin doesn’t cause intestinal failure.
• October 13, 2011 ... “Temporarily” TPN dependent.
• 8 lines in first 3 months
• 1 line in 25 months
  – Neurotic
  – CHG allergy
  – Stephanie/VA team
  – Ethanol Lock Therapy
- Doctor
- Nurse
- Family
Collaboration
10 Things I Have Learned In the Hospital
1. Be Organized
2. Be on Guard
3. Know the Chain of Command
4. Get it in the Orders
5. Exchange Information, Don’t Demand
6. Use My Resources Well
7. Have Emotional Power

Passive  Assertive  Aggressive
8. Be Emotionally Centered
9. Looks Matter
10. I Cannot Do This Alone
“Because they stand on a wall and say nothing is going to hurt you tonight. Not on my watch.”

From A Few Good Men: Lieutenant Commander Joanne Galloway (Demi Moore)