Partnering to Accelerate the Rate of Positive Change: The Experience of Lauren’s Hope Foundation & the NICU at Lehigh Valley Health Network

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Partnering to Accelerate the Rate of Positive Change: The Experience of Lauren’s Hope Foundation & the NICU at Lehigh Valley Health Network

Lorraine A. Dickey, MD, MBA, FAAP¹ and Ann Flood²

¹Lehigh Valley Health Network, Allentown, Pennsylvania; ²Lauren’s Hope Foundation

- Sharing Lauren’s story contributed to building trust and relationships between Lauren’s Hope Foundation and the LVHN NICU prior to undertaking this major project
- The degree of coordination required within a large hospital network to accomplish this project took much longer time than members of Lauren’s Hope Foundation initially imagined
- Change was accelerated by both partners acting in synergistic ways to align their missions and meet common goals

**Key Discoveries**

- Don’t be afraid to approach the hospital
- Ensure missions of foundation & hospital are aligned
- Expect setbacks but continue to persevere
- Offer assistance to facilitate project

**March 2007: Olympic Cool-Cap + aEEG**
- Construction FDA approved Olympic Cool-Cap as a new device for infants with Hypoxic-Ischemic Encephalopathy which can cause brain injury and severe neurological deficits. Up to 20% of infants with HIE die and another 25% suffer permanent disability.
- Cool-Cap provides selective head cooling during the first 72 hours of life by delivering a steady flow of water through a cap placed over the infant’s head.
- The Cool-Cap was found safe and effective in a study of 234 infants with moderate to severe HIE. At 18 months there were fewer deaths and severe neurological deficits in the cooled group compared with the control group.

**2003: Lauren Born -**
- Before Cooling Therapy available

**2008: Lauren’s Hope Foundation Founded**
- **Mission**: To enhance the lives of and give hope to brain injured children and their families by planning social events and providing full/partial funding for specialized therapies or equipment not covered by insurance.
- **Vision**: Bring neonatal therapeutic hypothermia therapies to the greater Lehigh Valley area.
- **Process**: Choose NICU: Lehigh Valley, Approach Development to donate one head cooling unit, Budgeted operating cost center, Initial meeting with NICU Medical Director → May 2010

**2010: LVHN NICU Medical Director - Response & Counter-Offer**
- Insufficient infrastructure to responsibly accept proposal at time
- Babies transferred to Philadelphia
- **Counter-Offer**: Involvement in PFCC activities of the NICU and LVHN, Continue to build relationships until such time offer could be accepted

**2009: Willa Born -**
- Received Head Cooling Therapy

**LHF Interim PFCC Involvement**
- Family faculty presentation to Dept. of Pediatrics
- Sharing Lauren’s story
- Focus on how the delivery of bad news could be improved

**2011: Pediatrics NICU Patient-Centered Experience Implementation team**
- Lauren’s Hope Foundation CEO added to major PCE project
- Inside look at how the larger Lehigh Valley Health Network healthcare system operates

**Spring 2011: Initial Meetings**
- Lauren’s Hope Foundation is a Full Partner with NICU:
  - New experience
  - NICU Therapeutic Hypothermia Committee includes:
    - CEO & members of the Board, LHF
    - Parents of baby who underwent cooling (Willa’s parents)
  - Estimation of time: 2 years
  - 1 year to bring a full interdisciplinary committee together due to competing projects & lack of infrastructure/staff
  - Once committee formed, estimate 1 year until neonatal hypothermia could be offered as a therapy in our NICU

**Advice for Other Foundations**

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**July 2012: Synergistic Actions**
- **Accelerated Change**
  - Synergistic actions with common goals:
    - Cultural & technical changes were accelerated through the synergistic efforts of members of Lauren’s Hope & LVHN NICU
    - New: Development of neonatal hypothermia program
    - Not envisioned prior to being approached by Lauren’s Hope Foundation

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