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

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**Key Discoveries**

- 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.

**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.

**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

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

**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

**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
- LVHN 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

**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
    - New: Development of Newborn Specialty Center
      - Not envisioned prior to this project

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**Advice for Other Foundations**

- 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