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, FAAP
Lehigh Valley Health Network, Lorraine_A.Dickey@lvhn.org

Ann Flood
Lauren's Hope Foundation

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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

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.

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

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

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

April 2012: Newborn Specialty Center
- 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

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

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

Spring 2011: 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

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