

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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**2003:
Lauren Born -**

- Before Cooling Therapy available

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.



**2009:
Willa Born -**

- Received Head Cooling Therapy

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

2003

2004

2005

2006

2007

2008

2009

2010

2011

2012

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

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

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

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