TRANSFORMING CARE FOR MEDICALLY COMPLEX INFANTS: ACCOMPLISHMENTS & FUTURE DIRECTIONS OF THE CHNC AND CHND

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Prepared by the CHNC Executive Committee:

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Much of the work of the CHNC has been made possible through the support of our childrens hospitals

Please visit www.thechnc.org for more information
The Children’s Hospitals Neonatal Consortium (CHNC: www.TheCHNC.org), is a quality outcome organization for neonatology leaders based in Level IV neonatal intensive care units (NICUs). The CHNC formed in 2006 and partnered with the Child Health Corporation of America (now Children’s Hospital Association (CHA)) to develop the Children’s Hospitals Neonatal Database (CHND) which was launched in 2010. From a 17 member institution collaborative in 2010, the CHND has grown to 34 participating sites in 2017. In 2017 the CHND transitioned from CHA to a new registry partner, Velos, however the goals of the consortium remain the same.

CHND was developed to meet the data acquisition and analytics required for comparative quality and outcome measures for the unique population of medically complex neonates and infants treated in NICUs (Level IV NICU patients) at children’s hospitals. Many of these high acuity infants have surgical problems, congenital anomalies or serious acquired complications of preterm birth. With an average 25-day length of stay and the multiple services they require after discharge, these infants represent one of the highest resource utilization groups of any pediatric population. CHND is the largest clinically valid data set for this unique patient population. In addition to clinical outcomes, CHND records have been linked to PHIS (CHA’s administrative dataset) to analyze cost variation for disease-specific patient populations. These linked analyses can provide patients, providers, and organizations with comparative data on both clinical outcomes and resource utilization in these medically complex infants.

In the current era when the population health of medically complex infants is a focus for our hospitals and CHA, the value of delivered health care must be assessed as the US spends approximately 20% of its gross domestic product (GDP) on health care. NICU patients in Children’s Hospitals represent only 7-8% of the patient population for these hospitals, but because of their complex care needs and long length of stay, with respect to resource utilization, this patient population represents 23% of the patient days and 21% of the charges of a Children’s Hospital. Therefore it is imperative that we invest and apply in key clinical resources like CHND that marry pediatric outcomes to measures of resource utilization captured both with the CHND and in other datasets in order to improve the quality of care and optimize expenditures in the care of medically complex children.

This document outlines the major milestones and accomplishments achieved through this collaboration and data analyses.
ACCOMPLISHMENTS

- **Engagement of an interdisciplinary group of neonatal experts**
  - CHNC established the vision and data elements to develop a robust clinical data set for this unique population
  - Neonatologists, advanced practice nurses, neonatal nurses, infection control practitioners, anesthesiologists, and pediatric surgeons volunteered to develop quality and research initiatives across participating institutions

- **Data design that focuses on this unique population of NICU infants**
  - Fills a gap in existing databases (e.g., Vermont-Oxford Network (VON) or VPS, Inc.) in order to capture needed information about the delivery of neonatal quaternary critical care
  - Captures the disease-specific data elements, practices and outcomes needed to develop valid clinical predictions
  - Designed to provide granularity and details on clinical diagnoses that are frequently inaccurately captured in administrative datasets based on billing codes
  - Allows linkage to PHIS and other administrative datasets for matching of clinical diagnoses with resource utilization data
  - Harmonized data elements with key national databases and registries (VON, CPQCC, ELSO, NICHD, CDH registry, NSQIP, NHSN)
  - Focused on disease-specific care practices and outcomes

- **Recognized by U.S. News & World Report (USNWR) Best Children’s Hospital Survey:**
  - CHND participation and CHND measures were scoring criteria in the 2014 - 2016 surveys
    - Based on CHND target benchmark data, four new objective patient-specific metrics were added to the Neonatology Survey over the past 4 years:
      - Rate of breastfeeding at discharge
      - Rate of post-operative hypothermia
      - Rate of admission temperature in target range in infants receiving hypothermia treatment on transport
      - Rate of unintended extubation
      - Percent of growth metrics documented at discharge
    - In the 2016 USNWR results for best children’s hospitals, 8/10 top neonatology programs and 10/11 in the honor roll list of top children’s hospitals are CHND participants.

- **Multi-center CHND QI Collaboratives are improving care and lowering costs**
  - SLUG BUG, demonstrated a 20% decrease in central line associated bloodstream infections with $69,000 of attributable cost savings per each averted infection
    - Centers sustained low rates for 19 months across 17 level IV NICU
    - Sterile tubing change was identified as an important factor in reducing central line infection rates
  - STEPP IN (Safe Transition and Euthemia in the Peri-operative Period In Neonates), has demonstrated improvement in patient safety and coordination of care and patient safety in the perioperative period
    - 47% decrease in post-operative hypothermia; specific processes were identified to impact outcome
    - Decreased post-operative communication failures by 21% and post-operative respiratory care failure by 64%
○ STEPP IN next STEPPs collaborative to address peri-operative safe patient practices and pain management began April 2017
○ See additional details in the CHND/CHNC CIQI White Paper

• Representing the Consortium, CHNC leaders are invited participants on key national/international initiatives that are leading to the standardization and optimization of quaternary neonatal care
  ○ Representation on the Vermont Oxford Neonatal Database Advisory Board, the major worldwide benchmarking database for neonates with common neonatal diseases
  ○ Representation on the “Optimal Resources for Children’s Surgical Care” task force of the American College of Surgeons that developed new guidelines defining the resources hospitals need to deliver surgical care for children both safely and effectively
  ○ Largest quaternary NICU in Canada a participant
  ○ Participated in a joint pediatric surgery/quaternary neonatology symposium presentation at the Fall 2015 American Academy of Pediatrics (AAP) meeting, in collaboration with the Sections of Neonatal Medicine and Pediatric Surgery
  ○ Representation on the Pediatric Terminology Governance Committee, an initiative of the National Institute of Child Health and Development (NICHD) and Pediatric EHR Data Sharing Network (PEDSNet) supporting terminology harmonization
  ○ Participation in the creation of the Neonatal Research Network Terminology, an initiative harmonizing the terminologies of the Vermont-Oxford Network, the NICHD, and the CHND
  ○ Leadership (Co-Chair) on the Child Health Work Group of Health Level Seven International, which develops interoperability standards for Electronic Health Record Functional Profiles and Clinical Document Architecture (CDA) used in quality reporting and health information exchange
  ○ Primary leadership in developing of the “Essential Information for Children with Special Healthcare Needs CDA,” which enables electronic exchange of important information about the patient-centered clinical needs for medically complex infants and children and their primary and subspecialty providers, in order to support and facilitate transitions of care to new medical environments

• Promoting international neonatal interdisciplined education focusing on quaternary care NICU’s
  ○ The CHNC conducts the only educational symposium focusing on quality improvement, program development and research for the unique population of Level IV NICU patients. The size and scope of these meetings are growing each year
    ○ “CHNC: Optimizing Perioperative Care of the Neonate and Young Infant,” Philadelphia, PA, 2012
    ○ CHNC/CHND Quality and Research Symposium, Sept 2015
    ○ CHNC/CHND Quality and Research Symposium, Sept 2016
    ○ CHNC/CHND Quality and Research Symposium, Oct 2017

• Providing short-term outcome data, including survival to hospital discharge in uncommon to rare diseases to guide clinicians in their patient care and in counseling families
• Providing the infrastructure to observe risk-adjusted outcomes for each disease of interest, to inform stakeholders in healthcare delivery for these populations
  o Begins to quantify the value of care for medically complex infants when relating these outcomes with resource utilization
• Disease-specific severity-of-illness risk adjustment tools under development
  o Severe bronchopulmonary dysplasia (BPD) tools completed
  o Congenital diaphragmatic hernia (CDH) and others in progress
• Inter-center variation in resource utilization, costs, and outcomes across sites is strikingly apparent in CHND
  o Benchmarking data from CHND allowed one center to reduce length of stay by 33% among infants with gastroschisis
• Analytics to date
  o Five major focus groups, composed of site sponsors from CHND/C and invited multidisciplinary experts in the field, have reviewed in-depth data on specific populations, with a number of peer reviewed publications to date (Appendix I).
  o Scientific presentations on disease-specific outcomes have been presented at key academic societies’ meetings

**FUTURE DIRECTIONS and Return on Investment (ROI)**

In a very short period of time, the capital outlay by 34 participating hospitals and CHA, and the time commitment by clinicians, have rapidly generated new knowledge about these patients and successful quality improvement initiatives.

**Disease-specific analyses** are the power of the CHND. Unlike other patient populations, such as short-stay acute PICU patients or general pediatric inpatients, the patient population in a quaternary NICU has a long length of stay, with varying disease processes that require in-depth analyses to determine best practices that will lead to improved care and outcomes. Therefore, future goals of the CHND include:
  o Continue to provide key objective outcome metrics relevant specifically for this patient population for public and other reporting (eg US News and World Report, etc)
  o Define disease specific treatment variability across sites, particularly related to LOS, resource utilization and outcomes
  o Determine most effective treatment approaches within this variability, and make recommendations on best practice
  o When new practices are implemented, measure outcome and success in improvement in clinically important areas, i.e., care, survival, length of stay. In addition, through data linkages with PHIS, determine best resource utilization for these key patient populations
  o Provide data for resource utilization expectations and advocate for medically complex patients using the data-driven platform generated
  o Simplify data access for both local and comparative data
  o Develop quality dashboards with more contemporaneous access to data
  o Identify and disseminate best practices and promote through QI implementation across sites
Appendix I:

CHND/CHNC Publications


Presentations at Scientific Meetings 2017

1. Yanowitz TD; Walek, S; Zaniletti I; Sharma J; Brozanski B; Sullivan K; DiGeronimo R; Piazza AJ; Wadhawan R; Murthy K and Children's Hospital Neonatal Consortium Surgical NEC Focus Group: Does the Initial Procedure for Surgical Necrotizing Enterocolitis Really Matter? At the "Necrotizing Enterocolitis Symposium: A transdisciplinary approach to improving outcomes." Sponsored by the NEC Society and the UC Davis Health System Office of Continuing Medical Education and Division of Neonatology. April 2017

PAS Presentations 2017

1. End of Life Care in Regional Level IV Neonatal Intensive Care Units (NICUs): Infants of older gestational ages are more likely to die without CPR: A report from the Children’s Hospitals Neonatal Consortium (CHNC). Poster presentation with Kevin Sullivan as presenting author

2. Declining Neonatal Mortality in Regional Level IV Neonatal Intensive Care Units (NICUs): An initial report from Children's Hospitals Neonatal Consortium (CHNC). poster presentation with Kevin Sullivan as presenting author

3. Intercenter variation (ICV) in anti-epileptic drug (AED) therapy in neonates with hypoxic-ischemic encephalopathy (HIE): A report from the Children’s Hospitals Neonatal Consortium (CHNC), poster presentation with Maria Dizon as presenting author

4. The Impact of Pulmonary Hypertension in Preterm Infants with severe BPD: A Multi-Center Comparison of NICU and Readmission Outcomes. Poster presenting with Joanne Lagatta as presenting author


PAS Presentations 2016


5. Murthy K; Gien, J; Pallotto EK; Brozanski BS; Chicoine L Zaniletti I; Seabrook R; Porta N; Keene S; Alapathi D; Rintoul N; Grover T and the Children’s Hospital Neonatal Consortium Congenital Diaphragmatic Hernia Study: In-Hospital Weight Gain and Survival in Infants with Congenital Diaphragmatic Hernia

6. Yanowitz TD; Zaniletti I; Sharma J; Brozanski B; Sullivan K; DiGeronimo R; Piazza AJ; Wadhawan R; Murthy K and Children’s Hospital Neonatal Consortium Surgical NEC Focus Group: Does the Initial Procedure for Surgical Necrotizing Enterocolitis Really Matter?
PAS Presentations 2015


2. Porta NFM, Lagatta JM, Troug WE, Zaniletti I, Savani RC, Nelin LD, Grover TR, Murthy K. *Inter-center Variation in Death or Tracheostomy Placement in Infants with Severe Bronchopulmonary Dysplasia*

3. Javier M, Murthy K, Gotteiner N, Porta NFM. *Right Ventricular Size Is Related To Death or Tracheostomy Placement in Infants With Severe Bronchopulmonary Dysplasia*


8. Riley MM, Goldbach M, Yanowitz TD, Morowitz, M, Vats K, Brozanski BS. *Interdisciplinary Collaboration To Reduce Hospital Stay for Neonates With Gastrochisis*
Appendix II:

The Children's Hospital Neonatal Database

2017 Membership

1. Alfred I. duPont Hospital for Children, Wilmington
2. All Children’s Hospital Johns Hopkins Medicine, St. Petersburg
3. American Family Hospital, Madison
4. Ann & Robert H. Lurie Children’s Hospital of Chicago
5. Arkansas Children’s Hospital, Little Rock
6. Boston Children's Hospital
7. Cincinnati Children’s Hospital
8. Children’s Healthcare of Atlanta at Egleston
9. Children’s Healthcare of Atlanta at Scottish Rite
10. Children’s Hospital and Medical Center, Omaha
11. Children’s Hospital Colorado, Denver
12. Children’s Hospital of Orange County
13. Children’s Hospital of Pittsburgh of UPMC
14. Children’s Hospital of Wisconsin, Milwaukee
15. Children’s Medical Center Dallas
16. Children’s Mercy Hospitals and Clinics, Kansas City
17. Children’s National Medical Center, Washington, DC
18. Children’s of Alabama, Birmingham
19. Children’s Hospital Los Angeles
20. Children’s Hospital of Michigan, Detroit
21. Cook Children's Medical Center, Fort Worth
22. Florida Hospital for Children, Orlando
23. Hospital for Sick Children, Toronto, Ontario
24. Le Bonheur Children’s Hospital, Memphis
25. Nationwide Children’s Hospital, Columbus
26. Primary Children’s Hospital, Salt Lake City
27. Rady Children’s Hospital, San Diego
28. Riley Children’s, Indianapolis
29. Seattle Children’s Hospital
30. St Christopher’s Hospital for Children, Philadelphia
31. St. Louis Children’s Hospital
32. Texas Children’s Hospital, Houston
33. The Children’s Hospital of Philadelphia
34. UCSF Benioff Children’s Hospital Oakland
Appendix III:
The Children’s Hospital Neonatal Consortium Board of Directors 2017

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