



**NeoQIC Family  
Engagement Quality  
Improvement  
Collaborative**

**Living with Chronic Lung Disease: Perspectives of Families  
23rd Braden E. Griffin, MD Memorial Symposium  
November 18, 2022 | Worcester, MA**

# Objectives

- Provide attendees with insight into parent perspectives on respiratory care in the NICU
- Illustrate examples of Quality Improvement to improve family member involvement in care in the NICU
- Highlight examples of efforts to increase family member education and comfort about their infant's lung disease

# NeoQIC Respiratory Care Collaborative Activities

- Local Center Quality Improvement
- Massachusetts VON Data Collection
- Practice Surveys
- Webinars & Learning Sessions
- Quality Improvement Toolkit
- Guideline Database
- Publications and Literature Collection
- Active subgroup for collaborative QI

[www.neoqicma.org/rcc](http://www.neoqicma.org/rcc)

# NeoQIC Respiratory Care Collaborative Activities

- Quarterly webinars and twice/year in-person meetings
- Expert Quest Speakers
- Forum for team sharing on improvements
- High-yield didactics on QI methods and family engagement topics
- Platform for tracking data improvement

<https://www.neoqicma.org/family-engagement>

# Agenda

1. Parent Video
2. Discussion with Family Member Guests
3. FiCare Program at SSH
4. Highlights of Other Programs

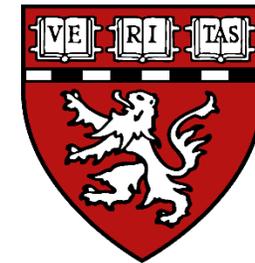


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# Modified Family Integrated Care in a U.S. Neonatal Intensive Care Unit: Nursing perspectives and effects on parents

**Zuzanna Kubicka**  
**Assistant Professor of Pediatrics**  
**Harvard Medical School**  
**Division of Newborn Medicine**  
**Boston Children's Hospital**



No disclosures



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# Background-original RCT trial



## Effectiveness of Family Integrated Care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial

*Karel O'Brien, Kate Robson, Marianne Bracht, Melinda Cruz, Kei Lui, Ruben Alvaro, Orlando da Silva, Luis Monterrosa, Michael Narvey, Eugene Ng, Amuchou Soraisham, Xiang Y Ye, Lucia Mirea, William Tarnow-Mordi, Shoo K Lee, for the FICare Study Group and FICare Parent Advisory Board\**



# FICare Cluster RCT summary

26 NICUs from Canada, Australia, and New Zealand.

Each center randomized to provide FICare or standard NICU care

## Infant's inclusion criteria

- <33 weeks GA
- No or low level of respiratory support (NC, CPAP, NIPPV)

## Exclusion criteria

- Palliative care
- Life threatening congenital anomaly
- Unlikely to survive
- Receiving invasive ventilation
- Planned early transfer

## Parents inclusion criteria

- Present in the NICU for at least 6 h/ day, 5 days/ week
- Attend educational sessions and medical rounds at least 3x/ week
- Actively care for their infant

## Exclusion criteria

- Unable to participate due to health, social, language barrier



# Previously published evidence from outside the US

- Cluster-randomized controlled trial (RCT) reported improved infant and parental outcomes in the group of parents participating in FICare compare to standard NICU care (increased infant weight gain and exclusive breast milk feeding rates as well as lower parental stress and anxiety scores)
- Prospective follow-up from the original RCT showed improved behavioral skills (self-regulation), neurodevelopmental outcomes (motor development), lower maternal stress scores and improved child behavioral outcomes at 18 months post-conceptual age.
- Other studies utilizing this approach similarly reported improved breastfeeding rates and suggested a reduced overall length of stay.
- One center reported higher infant scores on the mental development index and psychomotor development index at 18 months for infants
- Additional qualitative analyses suggested improved parent confidence, communication, increased parental involvement and positive feelings about their role in their infant's care.



# Background

- All the studies originating from countries with universal healthcare system and guaranteed paid maternity leave (Canada, Australia, New Zealand, China and Great Britain)
- To date, no studies demonstrating feasibility of FICare implementation and effects on parental outcomes have been published in a US healthcare setting
- Ongoing work on FICare feasibility in CA

## Paid Family Leave in the US



# SSH NICU modified FICare model

- Model enabling NICU parents to become active participants in their infant's care, rather than visitors.
- Created with active input from former parents
- In our setting it includes:
  - 1) providing education for parents utilizing a smart phone application (app)
  - 2) “hands-on coaching” by NICU nurses/multidisciplinary staff
  - 3) daily participation in medical rounds.
  - 4) additional elements: parents support group, “bead program” not part of the study



# SSH modified FICare model

- The educational program consists of one-on-one bedside teaching by different disciplines (i.e., nursing, nutritionists, etc.) =“hands-on skills coaching”
- Daily parental participation in multidisciplinary rounds either in person or by speaker phone (NICU parents overwhelmingly preferred to receive phone calls from the rounding team over tele-video calls).
- Utilization of a mobile phone application (app), *SSH NICU Ficare App*, designed and built by in-house NICU staff while incorporating feedback from former NICU parents.
  - ❖ serves as a supplemental educational resource for parents
  - ❖ each section concludes with an optional quiz parents can complete at their leisure.
  - ❖ does not feature any report back or communication with staff capabilities
  - ❖ completion of the educational sections is not a requirement for participation in the FICare program.
- FICare model offered to all families during prenatal consultation, if conducted, or shortly after an infant’s NICU admission regardless GA/LOS including families with LEP
- No required number of hours to participate
- No required classes



South Shore Health NICU



 <b>ORIENTATION TO FICARE</b>	 <b>DEVELOPMENTAL CARE</b>
 <b>BASIC SKILLS CARE</b>	 <b>FEEDING YOUR BABY</b>
 <b>DISCHARGE</b>	 <b>TOOLS FOR PARENTS</b>



< Back Tools



- PARENTS' FIC SUPPORT
- LACTATION SUPPORT
- BABY WEIGHT
- DIAPER LOG
- PHOTO BOOTH
- JOURNAL
- FEEDINGS
- KANGAROO CARE TIMER
- PUMPING



## Types of Respiratory Support



- CPAP – continuous positive airway pressure
  - Provides constant pressure into lungs and “air sacs” to keep them open
  - Helps make breathing easier
- NIPPV – “non-invasive positive airway pressure ventilation”
  - Higher level of support than CPAP
  - Provides CPAP, along with a respiratory rate and an additional pressure
  - Aids in supporting their respiratory drive

## CPAP & NIPPV equipment



- Nasal Prongs
  - Aid with positioning
  - Identify correct/incorrect positioning
- Chinstrap
  - Used with NIPPV to prevent large amount of air pressure from escaping through their mouth
  - Want air pressure to go to lungs and not out the mouth

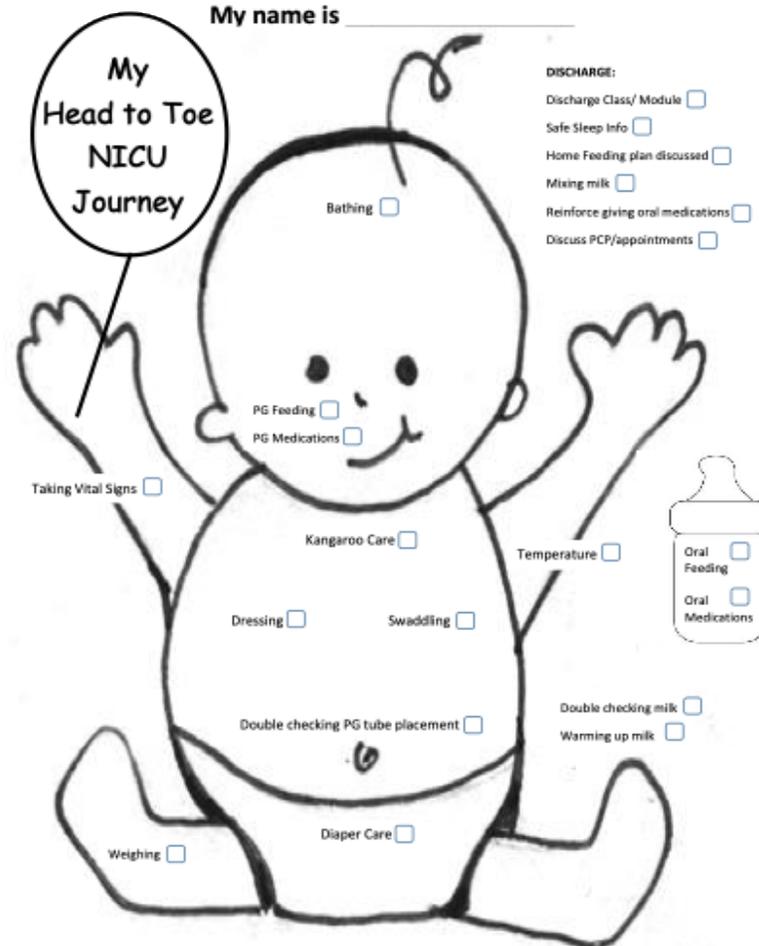
## Incorrect prong positioning



# Study Tools

## Infant Care Bedside Skills Checklist

1. Bathing
2. PG feeding
3. Administering PG medications
4. Taking vital signs
5. Kangaroo care
6. Taking temperature
7. Dressing
8. Swaddling
9. Oral feeding
10. Administering oral medications
11. Double checking PG tube placement
12. Double checking milk labels
13. Warming up milk
14. Weighing
15. Diaper care



Taught to you by your dedicated SSH NICU FICARE team MCU Shared Governance 12/2019

## Infant Discharge Checklist

1. Completion of discharge class/module
2. Discussing safe sleep information
3. Discussing home feeding plan
4. Discussing mixing milk
5. Reinforcing oral medication administration
6. Discussing follow-up appointments



# Study Design

- Quantitative questionnaire case-control design using both previously validated questionnaires (PSS:NICU) and questionnaires developed *de novo* by the research team
- Parental stress levels after NICU-wide FICare implementation were compared to controls who had completed the PSS(Parental Stressor Scale):NICU prior to FICare implementation as part of another study
- Within FICare group parents stratified by **degree of participation** evaluated associations **with:**
  - **1. parental stress**
  - **2. parental-staff communication**
  - **3. discharge readiness**
- Questionnaires captured nursing perspectives on FICare



# Results

78 parents completed PSS:NICU survey prior to FICare implementation; 90 completed the survey after NICU-wide implementation

Parental stress scores after FICare implementation were **significantly lower** compared to the pre-implementation control group (median stress score 61.5 (IQR 51,73) vs 94 (IQR 75.9, 112) respectively, ( $p < 0.001$ ))

Parental stress scores in all three subscales of PSS: NICU (baby looks and behaves, sights and sounds, parental role) were **significantly lower** in post-implementation group. ( $p < 0.001$ )

Parents who learned more than five infant care bedside skills had significantly lower stress levels, with a PSS: NICU score of 58.0 (IQR 44.0, 63.0), compared to those who learned 1 – 5 skills 64.5 (IQR 57.10, 78.50),  $p = 0.008$

Significantly higher PSS: NICU stress scores were found amongst parents who reported difficult financial demands ( $< 0.005$ ) and those who had to travel more than 30 minutes to get to the hospital ( $p < 0.001$ )

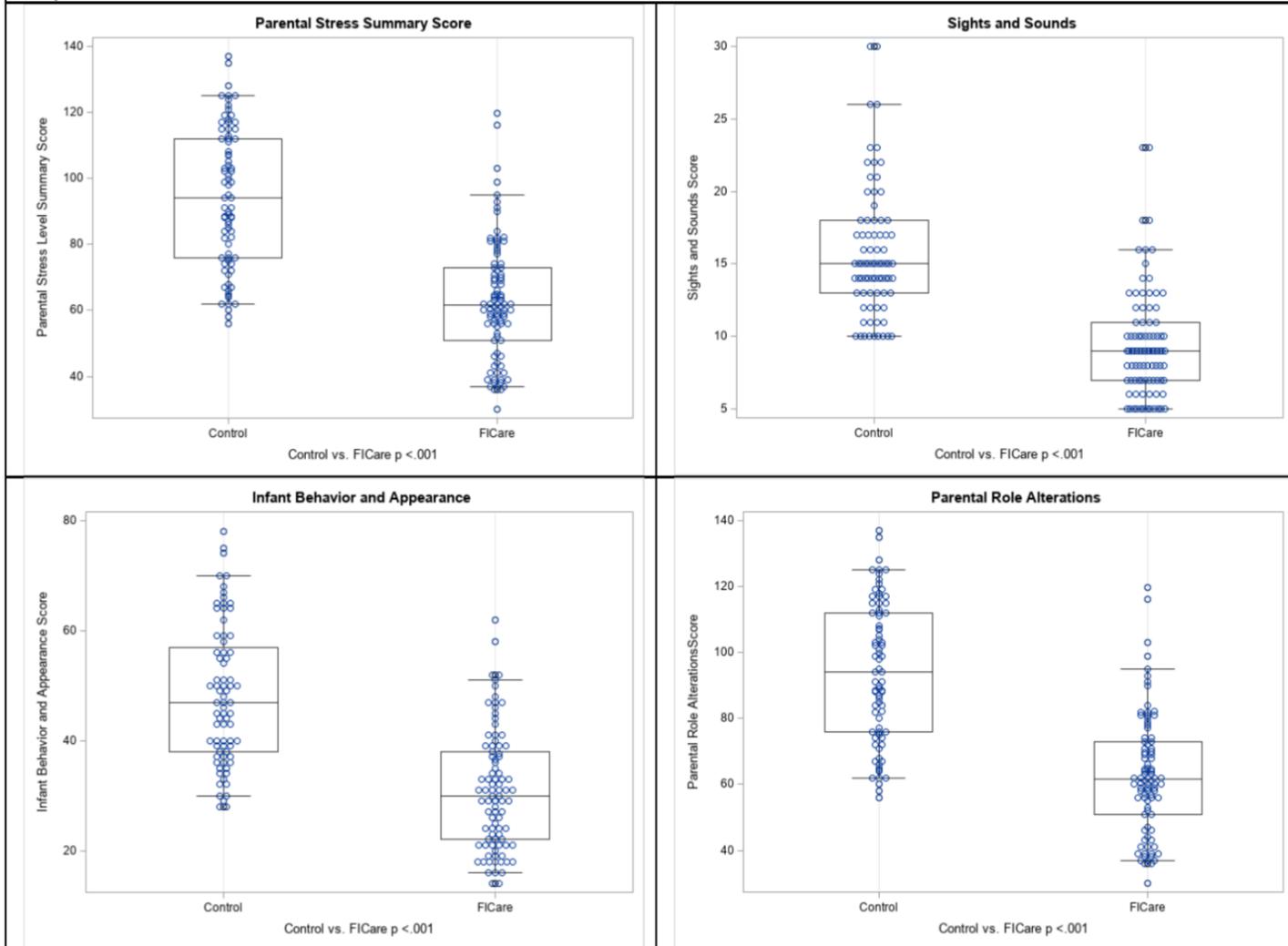
Within the post-implementation FICare group, increased parental utilization of the FICare app significantly increased parent-staff communication frequency ( $p = 0.007$ ) and parent-reported communication quality ( $p = 0.012$ )

Participation in rounds, utilization of the FICare app or completion of the infant care bedside skills list was not found to have a statistically significant effect on parent-reported discharge readiness

Statistical analysis of the association between communication and discharge readiness and parent participation in rounds was not found to be meaningful, as parents overwhelmingly participated in rounds (93%)



# Parental Stress Scores (PSS: NICU) Total and Subscales: Prior (Control) and After FICare Implementation



# Nursing perspectives

- **Perceived numerous positive effects for parents-nurses did believe that FICARE:**
- Improved quality of care infant receives ( $p < 0.0001$ )
- Improved parental communication with nurses ( $p < 0.0001$ )
- Improved parental participation in rounds ( $p < 0.0001$ )
- Improved parental readiness for discharge ( $p < 0.0001$ )
- Increased parental confidence in taking baby home ( $p < 0.0001$ )
- Did not increase parental stress ( $p < 0.0001$ )
- **With respect to their own work:**
- Nurses **did not believe** that FICare increased nursing work-related stress ( $p = 0.009$ )
- Nurses **believed** it has resulted in an increase in nursing job-satisfaction ( $p = 0.0001$ ) and has made it easier for them to discharge babies home to their parents ( $p < 0.001$ )







**QUESTIONS?**

Thank you!

**ZKUBICKA@SOUTHSHOREHEALTH.ORG**



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## QI Highlight

### Care Path for Discharge of Infants with Bronchopulmonary Dysplasia (BPD)

#### Training Program for Parents at CCMC NICU:

- An initial multidisciplinary meeting with parents
- Gradual introduction of knowledge material
  - to medication administration
  - assessing respiratory status
  - formula preparation and fortification of breast mil
  - monitoring the infant at home and recognizing signs to warrant concern
  - infant hygiene
- Documentation of parents' competencies by providers

# Care Path for Discharge of Infants with Bronchopulmonary Dysplasia (BPD)



Connecticut Children's NICU  
at UConn Health Center  
282 Washington Street  
Hartford, CT 06106

(Patient Identification)

## Integrated Care Plan – Discharge Home with BPD

Date of team meeting: \_\_\_\_\_ Parents instructed to sign up for CPR class. \_\_\_\_\_ BPD packet given to parents. \_\_\_\_\_  
CPR completed. \_\_\_\_\_

### INFANT CARE

1. Parents demonstrate the ability to provide basic infant hygiene and safety. \_\_\_\_\_
2. Parents verbalize developmental needs of the infant. \_\_\_\_\_
3. Parents verbalize indications of when to call the doctor. \_\_\_\_\_
4. Parents schedule extended stay/time for teaching. \_\_\_\_\_
5. Parents complete the Discharge Check-Off Sheet. \_\_\_\_\_

### VIDEOS

1. Back to Sleep \_\_\_\_\_
2. Shaken Baby \_\_\_\_\_
3. Car Seat Safety \_\_\_\_\_
4. RSV (if applicable) \_\_\_\_\_

### IMMUNIZATIONS

1. Hib \_\_\_\_\_
2. Hep B \_\_\_\_\_
3. Pneumococcal \_\_\_\_\_
4. Pediarix \_\_\_\_\_
5. Synagis \_\_\_\_\_

### PEDIATRICIAN

1. Parents instructed to identify a pediatrician. \_\_\_\_\_
2. Pediatrician's name: \_\_\_\_\_
3. First pediatrician appointment scheduled for: \_\_\_\_\_

### FINAL PREPARATION

1. Prescriptions given to parents. \_\_\_\_\_
2. Accuracy of home prescriptions verified by RN. \_\_\_\_\_
3. Parents demonstrate ability to safely place infant in car seat. \_\_\_\_\_
4. Car seat test done no earlier than 48 hours prior to discharge. \_\_\_\_\_

### MEDICATIONS

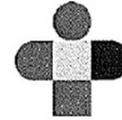
1. Parents are able to state the rationale of medications. \_\_\_\_\_
2. Parents are able to successfully draw up medications. \_\_\_\_\_
3. Parents are able to administer medications correctly. \_\_\_\_\_
4. Parents given home MAR. \_\_\_\_\_
5. Parents are able to document on home MAR. \_\_\_\_\_

### RESPIRATORY

1. Parents are able to assess respiratory status, including sleeping respiratory rate (SRR). \_\_\_\_\_
2. Parents are able to document SRR. \_\_\_\_\_
3. Parents are able to determine increased work of breathing. \_\_\_\_\_
4. \_\_\_\_\_

### NUTRITION

1. Discharge feeding plan is determined and initiated. \_\_\_\_\_
2. Care givers given instructions on preparing milk safely. \_\_\_\_\_
3. Arrangements made for special formula. \_\_\_\_\_
4. Recipe for formula provided and reviewed with parents. \_\_\_\_\_
5. WIC papers completed as needed. \_\_\_\_\_
6. Lactation Consultant consultation. \_\_\_\_\_



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at UConn Health Center  
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(Patient Identification)

## Integrated Care Plan – Discharge Home with BPD

### RESPIRATORY

Oxygen discontinuation: \_\_\_\_\_  
Extended Oximetry in Room Air: \_\_\_\_\_  
1. \_\_\_\_\_  
2. \_\_\_\_\_  
3. \_\_\_\_\_  
Need for monitor identified. \_\_\_\_\_  
Parents have signed the Parent Home Monitor Checklist. \_\_\_\_\_

Initials      Signature

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### CASE MANAGER

1. Assigned Case Manager is: \_\_\_\_\_
2. Case Manager makes contact with family. \_\_\_\_\_
3. Case Manager talks with parents about home care agencies. \_\_\_\_\_

### DEVELOPMENTAL

1. Developmental assessment done and includes the ability to po feed. \_\_\_\_\_
2. EIP/Birth to Three information and developmental findings reviewed with family. \_\_\_\_\_
3. Birth to Three referral to be made upon discharge. \_\_\_\_\_

### CONSULTS & PROCEDURES

Term Cranial Ultrasound \_\_\_\_\_  
Sleep Study \_\_\_\_\_  
pH probe \_\_\_\_\_  
Pulmonary Consult \_\_\_\_\_  
Swallow study \_\_\_\_\_  
Circumcision \_\_\_\_\_

### SOCIAL WORK

1. Contact made with family per Social Work department practice. \_\_\_\_\_

### HEARING SCREENING

Date: \_\_\_\_\_  
Pass: \_\_\_\_\_  
Referred: \_\_\_\_\_

### DISCHARGE

Weight: \_\_\_\_\_ kg  
Height: \_\_\_\_\_ cm  
Head Circ.: \_\_\_\_\_ cm

*\* Please sign/date here if patient is transferred to another facility prior to completion of BPD teaching:*

*\* Parents = Parents or identified care givers.*

## QI Highlight

### Improving parental education on bronchopulmonary dysplasia (BPD)

**Global aim:** Improve parent experience, engagement, and understanding of the medical care for parents of infants with BPD

#### Specific Aims:

- To **provide parental education to greater than 75% of families** with infants with moderate/severe BPD admitted to NICU within one year
- To **improve parental understanding of BPD for parents of moderate/severe BPD infants by 20% from baseline** within one year measured by post-education surveys
- To **improve parental satisfaction of NICU multidisciplinary care for parents of moderate/severe BPD infants by 20%** within one year measured by post-education Likert scale surveys



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See more: [www.neoqicma.org/rcc](http://www.neoqicma.org/rcc)

Email: [jonathan.levin@childrens.harvard.edu](mailto:jonathan.levin@childrens.harvard.edu)



# QI Highlight

## Improving parental education on bronchopulmonary dysplasia (BPD)

### Quotes from Parental Pre-Survey Data

*"In my child's chart, I see the acronym BPD a lot, but in meetings we discuss CLD. I don't know if there is a difference."*

*"My child was premature, but her primary issue is with the airway. We were unsure how a trach would effect the lungs."*

*"My understanding is lung issues related to being premature will resolve over time as he grows."*

*"Additional information on modes of ventilation would be helpful."*

### PDSA Cycle 1: Use of educational tool by Pulmonology team during consult

**What does it look like?**

Healthy Lungs vs Lungs with BPD

**How does it affect the lungs?**  
In BPD, lungs are underdeveloped and immature due to the disrupted growth of air sacs and blood vessels.

**What are tools to diagnose and evaluate BPD?**

Your baby may require any of the following during their NICU course:

- Imaging studies**
  - Chest X-ray
  - Chest CT
  - Echocardiogram
- Blood work**
  - Blood gas levels
  - Electrolytes
  - Genetic testing (if applicable)
- Procedures**
  - Airway evaluation
    - Direct Laryngobronchoscopy (DLB): video scope to look at upper airway
    - Flexible Bronchoscopy: video scope to look at lower airway
  - Swallow study
- Assessments**
  - Evaluation of growth, nutrition, feeding
  - Developmental assessments (physical and occupational therapy)

**What are treatments for BPD?**

- Breathing treatments for BPD are devices that support gas exchange and deliver oxygen or pressure to your baby. Examples of these devices are:**
  - Nasal cannula
  - Continuous positive airway pressure (CPAP)
  - Bilevel positive airway pressure (BiPAP)
  - Breathing tube and ventilator
- Medications that are used to treat BPD include:**
  - Caffeine
  - Diuretics to reduce water in the lungs (e.g. furosemide/Lasix®, chlorothalidide/Diuril®)
  - Steroids to reduce inflammation (e.g. prednisolone, methylprednisolone, dexamethasone, hydrocortisone)
  - Inhaled breathing treatments (e.g. albuterol, levalbuterol/Xopenex®, ipratropium/Atrivent®, budesonide/Pulmicort®, fluticasone)
- Babies with BPD often need feeding therapy with the use of a nasogastric (NG) or nasojejunal (NJ) tube.**
- Some will continue to require oxygen even after they leave the hospital.**
- Some will continue to require a mechanical ventilator even after they leave the hospital. For these babies, surgery may be needed for a more stable airway called a tracheostomy. These babies will also need a more stable feeding tube, called a gastrostomy tube (g-tube). Optimizing growth and nutrition are a key focus in treatment of BPD and encourage lung growth.**

**Who takes care of a baby with BPD after they leave the NICU?**

- Pediatrician**  
Just like the large team that works together in the NICU, a team of many specialists will help take care of your baby once they are discharged home. This team will work closely with your child's pediatrician who will be the leader in coordinating visits and communicating with the other members of your child's medical team.
- Lungs**  
Your baby will see a lung specialist (pulmonologist).
- Feeding**  
Your baby may see a nutritionist, a specialist that will help monitor your baby's diet and growth. Some babies require help learning to feed with a feeding therapist.
- Brain/Development**  
Your baby will have an evaluation of their development through a program called early intervention, which will determine whether your baby will receive speech therapy and/or physical therapy. They will receive additional developmental testing at our NICU GrADS clinic.
- Other Subspecialty Care**  
Other specialists that your baby may see are an eye specialist (ophthalmologist) to monitor your baby's eyes and a heart specialist (cardiologist) to monitor your baby's heart.

Thank you!

Thank you to our  
family partners!

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