



PREMATURITY AND RESPIRATORY OUTCOMES PROGRAM

PID: _____

COMORBIDITIES OF PREMATURITY

DATE: ___/___/_____

AT WEEK 36, WEEK 40 PMA OR DISCHARGE,
WHICHEVER OCCURS FIRST

Cardio-Pulmonary

1. Did the baby have any of the following types of air leaks? []0 No []1 Yes

If Yes, indicate the type(s) of air leak by answering Questions 1a-1d:

1a. Pneumothorax: []0 No []1 Yes

If Yes, complete 1a1 and 1a2

1a1. Was a chest tube placed? []0 No []1 Yes

1a2. Has there been evidence of a bronchopleural fistula? []0 No []1 Yes

1b. Pulmonary Interstitial Emphysema (PIE): []0 No []1 Yes

1c. Pneumomediastinum: []0 No []1 Yes

1d. Pneumopericardium: []0 No []1 Yes

2. Did the baby have any pulmonary hemorrhages? []0 No []1 Yes

If Yes, complete 2a and 2b.

2a. Did these hemorrhages require transfusion of blood products? []0 No []1 Yes

2b. Did these hemorrhages require increased concentrations of supplemental oxygen and / or ventilator support? []0 No []1 Yes

3. Did the baby have a clinical diagnosis of Patent Ductus Arteriosus (PDA)? []0 No []1 Yes

3a. Was the PDA confirmed by echocardiogram? []0 No []1 Yes

Indicate if any of the following treatments were used to treat the suspected or confirmed PDA:

3b. Indomethacin (do not report any prophylactic Indomethacin given within the first 24 hours of life): []0 No []1 Yes

If Yes, indicate the first date of each distinct course of Indomethacin:

Month / Day / Year
First Course

Month / Day / Year
Second Course

Month / Day / Year
Third Course

3c. Ibuprofen: []0 No []1 Yes

If Yes, indicate the first date of each distinct course of Ibuprofen:

Month / Day / Year
First Course

Month / Day / Year
Second Course

Month / Day / Year
Third Course



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3d. Surgical Ligation:

No Yes

If Yes, date of surgery:

_____/_____/_____

4. Was a diagnosis of pulmonary hypertension made by a pediatric cardiologist?

No Yes

4a. If Yes, was this diagnosis based on (Check all that apply)

Echocardiogram

_____/_____/_____
Month / Day / Year
Date of Diagnosis

Cardiac catheterization

_____/_____/_____
Month / Day / Year
Date of Diagnosis

5. Was airway endoscopy performed by an ENT surgeon or pediatric pulmonologist?

No Yes

5a. If Yes, indicate clinical findings (check all that apply):

No abnormality noted

Tracheomalacia

_____/_____/_____
Month / Day / Year
1st Procedure

_____/_____/_____
Month / Day / Year
2nd Procedure

Laryngomalacia

_____/_____/_____
Month / Day / Year
1st Procedure

_____/_____/_____
Month / Day / Year
2nd Procedure

Subglottic stenosis

_____/_____/_____
Month / Day / Year
1st Procedure

_____/_____/_____
Month / Day / Year
2nd Procedure

Vocal cord paralysis (unilateral)

_____/_____/_____
Month / Day / Year
1st Procedure

_____/_____/_____
Month / Day / Year
2nd Procedure

Vocal cord paralysis (bilateral)

_____/_____/_____
Month / Day / Year
1st Procedure

_____/_____/_____
Month / Day / Year
2nd Procedure

Other, specify:

_____/_____/_____
Month / Day / Year
1st Procedure

_____/_____/_____
Month / Day / Year
2nd Procedure

6. Did the baby have a tracheotomy?

No Yes

6a. If Yes, indicate the procedure date:

_____/_____/_____



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7. Was Ventilator-Associated Pneumonia (VAP) suspected in this baby? ₀ No ₁ Yes

If **Yes** to 7, answer 7a – 7c.

7a. Did the baby have worsening gas exchange (e.g. O₂ desaturations, Increased oxygen requirements, or increased ventilator demand)? ₀ No ₁ Yes

7b. Did the baby have any of the following associated conditions (check all that apply)?

- Temperature instability with no other recognized cause
- Leukopenia (<4,000 WBC/mm³)
- Leukocytosis (≥ 15,000 WBC/mm³) and left shift (≥ 10% band forms)
- New onset of purulent sputum
- Change in character of sputum
- Increased respiratory secretions
- Increased suctioning requirements
- Apnea
- Tachypnea
- Nasal flaring with retraction of chest wall or grunting
- Wheezing
- Rales
- Rhonchi
- Cough
- Bradycardia (< 100 beats per minute)
- Tachycardia (> 170 beats per minute)
- None of the above

7c. Did the baby have serial chest radiographs with any of the following (check all that apply)?

- New infiltrate
- Progressive and persistent infiltrate
- Consolidation
- Cavitation
- Pneumatoceles
- None of the above

Infection

8. Did the baby have any blood culture-proven Sepsis? ₀ No ₁ Yes

8a. If **Yes**, indicate the type(s) of Sepsis:

- Bacterial Number of distinct episodes: ____
- Fungal Number of distinct episodes: ____
- Viral Number of distinct episodes: ____

8b. Presumed, but not culture-proven Sepsis? ₀ No ₁ Yes

If **Yes**, number of distinct episodes: ____

9. Did the baby have any culture-proven Meningitis? ₀ No ₁ Yes

9a. If **Yes**, indicate the type(s) of Meningitis:

- Bacterial Number of distinct episodes: ____
- Fungal Number of distinct episodes: ____
- Viral Number of distinct episodes: ____

9b. Presumed, but not culture-proven Meningitis? ₀ No ₁ Yes

If **Yes**, number of distinct episodes: ____



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10. Did the baby have upper respiratory tract infection of confirmed viral etiology?

No Yes

10a. If **Yes**, indicate the confirmed viral etiologies (check all that apply):

Influenza
Month / Day / Year
1st Diagnosis

Month / Day / Year
2nd Diagnosis

Para-influenza
Month / Day / Year
1st Diagnosis

Month / Day / Year
2nd Diagnosis

Rhinovirus
Month / Day / Year
1st Diagnosis

Month / Day / Year
2nd Diagnosis

Respiratory syncytial virus (RSV)
Month / Day / Year
1st Diagnosis

Month / Day / Year
2nd Diagnosis

Other, specify

Month / Day / Year
1st Diagnosis

Month / Day / Year
2nd Diagnosis

11. Did the baby have any other infections?

No Yes

11a. If **Yes**, indicate the infections (check all that apply):

Urinary tract infection
Month / Day / Year
1st Diagnosis

Month / Day / Year
2nd Diagnosis

Cellulitis
Month / Day / Year
1st Diagnosis

Month / Day / Year
2nd Diagnosis

Osteomyelitis
Month / Day / Year
1st Diagnosis

Month / Day / Year
2nd Diagnosis

Cytomegalovirus (CMV)
Month / Day / Year
1st Diagnosis

Month / Day / Year
2nd Diagnosis

Surgical wound infection
Month / Day / Year
1st Diagnosis

Month / Day / Year
2nd Diagnosis

Other, specify

Month / Day / Year
1st Diagnosis

Month / Day / Year
2nd Diagnosis



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Gastro Intestinal

12. Did the baby have Necrotizing Enterocolitis (NEC) Bell stage 2 or 3?

[]0 No []1 Yes

12a. If Yes, date of first medical diagnosis:

Month / Day / Year

12b. Were there any bowel perforations?

[]0 No []1 Yes

12c. Did the baby have surgery for NEC?

[]0 No []1 Yes

If Yes, indicate the surgical procedure(s) performed (check all that apply) and provide the date(s) of surgery:

[] Peritoneal drain

Month / Day / Year
1st Surgery

Month / Day / Year
2nd Surgery

[] Laparotomy

Month / Day / Year
1st Surgery

Month / Day / Year
2nd Surgery

[] Bowel resection

Month / Day / Year
1st Surgery

Month / Day / Year
2nd Surgery

[] Repair of Adhesion /
Strictures

Month / Day / Year
1st Surgery

Month / Day / Year
2nd Surgery

13. Did the baby have any Isolated Bowel Perforations not considered to be associated with NEC?

[]0 No []1 Yes

13a. If Yes, date of first medical diagnosis:

Month / Day / Year

13b. Did the baby receive any surgery for Isolated Bowel Perforations not considered to be associated with NEC?

[]0 No []1 Yes

If Yes, indicate the surgical procedure(s) performed (check all that apply) and provide the date(s) of surgery:

[] Peritoneal drain

Month / Day / Year
1st Surgery

Month / Day / Year
2nd Surgery

[] Laparotomy

Month / Day / Year
1st Surgery

Month / Day / Year
2nd Surgery

Ophthalmologic

14. Were any Retinopathy of Prematurity (ROP) examinations performed prior to discharge from the PROP study center?

[]0 No []1 Yes

15. Was this baby diagnosed with ROP?

[]0 No []1 Yes



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*AT WEEK 36, WEEK 40 PMA OR DISCHARGE,
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If **Yes**, answer the following questions:

15a. What was the worst stage ever reported in any zone?

___ Left Eye (1-5)
___ Right Eye (1-5)

15b. Did the baby undergo laser or cryo-surgery?

Left Eye: ₀ No ₁ Yes

Date of procedure: ___/___/___
Month Day Year

Right Eye: ₀ No ₁ Yes

Date of procedure: ___/___/___
Month Day Year

15c. Did the baby undergo Bevacizumab (Avastin) treatment?

Left Eye: ₀ No ₁ Yes

Date of procedure: ___/___/___
Month Day Year

Right Eye: ₀ No ₁ Yes

Date of procedure: ___/___/___
Month Day Year

15d. Did the baby undergo vitrectomy?

Left Eye: ₀ No ₁ Yes

Date of procedure: ___/___/___
Month Day Year

Right Eye: ₀ No ₁ Yes

Date of procedure: ___/___/___
Month Day Year

Neurologic

16. Did the baby receive a ventricular shunt?

₀ No ₁ Yes

16a. If **Yes**, provide the date of first shunt placement:

___/___/___
Month Day Year

Other Surgeries (excluding PDA ligation, surgery for NEC or Bowel Perforation, all surgeries for ROP, ventriculoperitoneal shunt placement, and tracheotomy)

1. Type of surgery: _____

Date of surgery: ___/___/___
Month Day Year

2. Type of surgery: _____

Date of surgery: ___/___/___
Month Day Year

3. Type of surgery: _____

Date of surgery: ___/___/___
Month Day Year

4. Type of surgery: _____

Date of surgery: ___/___/___
Month Day Year

5. Type of surgery: _____

Date of surgery: ___/___/___
Month Day Year



PREMATURITY AND RESPIRATORY OUTCOMES PROGRAM

PID: _____

DISCHARGE FORM

DATE: ___ / ___ / _____

1. What was the baby's discharge date?

Month ___ / Day ___ / Year _____

2. Where was the baby discharged to?

- ₁ Home
- ₂ Transfer to another hospital
- ₃ Baby died at study center*
- ₉₈ Other, specify: _____

NOTE: If the child dies at the study center, record date of discharge as date of death and complete a Death Form. All remaining information on this form should reflect information collected up to the time of death.

3. Was this baby enrolled in TOLSURF?

₀ No ₁ Yes

3a. If **Yes**, provide study specific Participant ID _____

4. Was this baby enrolled in the NRN Hydrocortisone for Extubation Trial?

₀ No ₁ Yes

4a. If **Yes**, provide study specific Participant ID _____

5. Was this baby enrolled in the NRN Generic database?

₀ No ₁ Yes

5a. If **Yes**, provide study specific Participant ID _____

6. Was this baby enrolled in any other randomized clinical treatment trials?

₀ No ₁ Yes

6a. If **Yes**, provide clinical trial name(s): _____

7. Was this baby enrolled in any other long term follow-up studies?

₀ No ₁ Yes

7a. If **Yes**, provide study name(s): _____

8. How many people normally live in your home including your baby (for at least 6 months of the year)? (Please select one)

- ₁ 2-3
- ₂ 4-6
- ₃ 7-10
- ₄ >10

8a. How many other children under 5 years old live in <baby's name>'s home?

___ children

8b. How many children between ages 5-12 years old live in <baby's name>'s home?

___ children

9. Is baby exposed to dogs, cats, or other furry animals at home?

₀ No ₁ Yes



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PID: _____

DISCHARGE FORM

DATE: ___ / ___ / _____

10. Will your baby receive any care outside of the home in the next year? _0 No _1 Yes _88 Unknown

11. Which one of the following three statements best describes smoking in <baby's name>'s home?

- _1 Smoking is allowed anywhere in the home
- _2 Smoking is limited to part of the house where <baby's name> rarely goes
- _3 Smoking is not allowed inside the home at all

12. Which one of the following five statements best describes smoking in the car?

- _0 Child rarely travels by car.
- _1 There is no smoking inside the car
- _2 Smoking occurs in the car only when <baby's name> is not inside
- _3 Smoking is sometimes allowed in the car
- _4 Smoking is usually or always allowed in the car

13. Please tell us what breathing and allergy problems run in the family (Check all that apply)

Symptoms	None/ Not applicable	Biological Siblings (any)	Biological Parents (one or both)
a. Asthma/Recurrent lung infections	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _2
b. Allergies/Hayfever	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _2
c. Eczema	<input type="checkbox"/> _0	<input type="checkbox"/> _1	<input type="checkbox"/> _2

14. How will <baby's name>'s health care be paid for primarily: (select only one)

- _0 No Insurance (self pay)
- _1 Private Insurance
- _2 Medicaid/Public Insurance



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CONTACT FORM

ADMINISTRATIVE

PID: _____

DATE: ____ / ____ / ____

****Please Note: This is an Administrative Form. All personal information provided will be held in confidence and will not be entered into the Data Management System Database.****

1. Child's name: _____
First _____ Last _____
- a. Child's nickname (if any) _____
- b. Child's sex Male Female
2. Child's birth date: _____
Month / Day / Year
3. Telephone Number: _____ - _____ - _____
4. Address: _____

Primary Contact Information

5. Name: _____
First _____ Last _____
6. Telephone Number: _____ - _____ - _____
7. Cell Phone Number: _____ - _____ - _____
8. Address: _____

9. Email address: _____

Mother's Contact Information

10. Is this the Primary Contact? No (Complete contact information) Yes (Skip to next section)
11. Name: _____
First _____ Last _____
12. Telephone Number: _____ - _____ - _____
13. Cell Phone Number: _____ - _____ - _____
14. Address: _____

15. Email address: _____



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CONTACT FORM

ADMINISTRATIVE

PID: _____

DATE: ____ / ____ / ____

Spouse/Partner's Contact Information

16. Is this the Primary Contact? No (Complete contact information) Yes (Skip to next section)

17. Name: _____
First Last

18. Telephone Number: _____ - _____ - _____

19. Cell Phone Number: _____ - _____ - _____

20. Address: _____

21. Email address: _____

Please provide the name and contact information of someone who is most likely to have your address in case we lose contact with you. It is helpful if this person does not reside with your child.

22. Name: _____
First Last

23. Telephone Number: _____ - _____ - _____

24. Cell Phone Number: _____ - _____ - _____

25. Address: _____

26. Email address: _____

Please provide the name and contact information of an additional person who is most likely to have your address in case we lose contact with you.

27. Name: _____
First Last

28. Telephone Number: _____ - _____ - _____

29. Cell Phone Number: _____ - _____ - _____

30. Address: _____

31. Email address: _____



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CONTACT FORM

ADMINISTRATIVE

PID: _____

DATE: ____ / ____ / ____

Pediatrician Contact Information

32. Name: _____
First _____ Last _____

33. Telephone Number: _____ - _____ - _____

34. Cell Phone Number: _____ - _____ - _____

35. Address: _____

36. Email address: _____

Other Health Professional's Contact Information

37. Name: _____
First _____ Last _____

38. Telephone Number: _____ - _____ - _____

39. Cell Phone Number: _____ - _____ - _____

40. Address: _____

41. Email address: _____