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Women & Infants Hospital
Neonatal Follow-Up Program
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Providence, RI 02905
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Home Care of the Infant with Chronic Lung Disease
A GUIDE FOR PARENTS
What is Chronic Lung Disease?
• Chronic Lung Disease (CLD) is the same as bronchopulmonary dysplasia (BPD).
• When a baby needs to be on a respirator and oxygen for a long time, it makes the lung tissue swell and scar.
• This causes the lung tissue to not develop normally.

What makes a baby at risk for CLD?
• Being born prematurely means the lungs are underdeveloped and stiff.
• Low birth weight, especially weighing less than 1500 grams (3 lb. 3 oz.)
• High concentrations of oxygen
• Using mechanical ventilation (respirator)
• GER (gastroesophageal reflux)
• Infections in the womb (chorioamnionitis)
• Patent Ductus Arteriosus (PDA), which is when the connection between the blood vessels of the heart and lung does not close after birth

What are the symptoms of CLD?
• Trouble breathing - when the baby’s nostrils move in and out, the ribs suck in, or there is grunting or fast breathing
• Low levels of oxygen in the blood and the need for oxygen support
• Poor weight gain

What is the BIT:S?
• BIT:S is the Brochopulmonary Dysplasia Interdisciplinary Team: Severe.
• BIT:S is a multidisciplinary team of pediatric heart specialists (cardiologists), lung specialists (pulmonologists), neonatologists with special interest in CLD, your NICU doctors, pharmacists and Neonatal Follow-Up Clinic doctors.
• The goal is to improve clinical care and outcomes for infants with severe CLD.
• If your baby has severe chronic lung disease, someone from BIT:S may talk to you.
• If your baby is seen by a BIT:S team member, you will be given more information and follow up.

What conditions can affect CLD?
Infections
• Common viruses – such as Respiratory Syncytial Virus (RSV) and the flu can make babies very sick.
• Infection can cause breathing to get worse quickly (fast breathing, ribs sucking in, nostrils moving in and out, or low blood oxygen).
• If you notice these things, call your doctor immediately.
• You can help lower the risk of infection.
  ○ ALWAYS wash your hands before touching your baby.
  ○ Keep your baby away from people who are sick.
  ○ Make sure your baby gets Synagis (RSV immunization) once a month during RSV season (November through March).
  ○ Flu vaccine is given after six months of age.
  ○ Before six months, protect your baby by having everyone else in the house get a flu shot.

Gastroesophageal Reflux (GER)
• GER is when the stomach contents back up into the esophagus (food tube between mouth and stomach).
• All babies have some reflux until they get bigger and stronger.
• Babies who have acid reflux may arch or cry after eating, wheeze, vomit or have poor weight gain.
• Some babies may be treated with thickened feeds or medicine.
• Talk to your doctor if you are worried about your baby’s feeding or reflux.

Pulmonary hypertension
• This is high blood pressure inside the lungs.
• Symptoms include difficulty weaning off oxygen, edema (swelling) or poor growth.
• Infants with pulmonary hypertension need to be followed by a pediatric heart doctor.

What are the goals of treatment for CLD?
• Keep your baby’s lungs healthy, which helps to:
  ○ Keep oxygen at a good level
  ○ Make it easier to breathe
  ○ Allow for adequate growth and nutrition
• Prevent infections
• Provide good nutrition to help the lungs heal
How can you help my baby?
The following treatments may help:
• Diuretics
• Short-acting bronchodilators
• Inhaled steroids
• Oxygen
• Nutrition
• Making sure no one smokes at home

Diuretics
• Their common names are Lasix® (furosemide), Diuril® (chlorothiazide), Aldactone® (spironolactone).
• They work by removing fluid from the lungs, like water pills.
• They are a liquid given by mouth or through a feeding tube.
• Side effects may include:
  ○ Dehydration - less wet diapers than usual, no tears, dry lips or mouth. If you see this, call your doctor.
  ○ Electrolyte (blood salts) abnormalities - It is very important to give the exact dose as prescribed. If you have questions about the dose, call your doctor.

Short-acting bronchodilators
• Their common names are albuterol (ProAir®, Ventolin®, Proventil®), levalbuterol (Xopenex®).
• They work by relaxing the muscles around the breathing tubes and making them wider.
• They are a liquid given through a nebulizer (breathing machine) with mask or through an MDI (pump) with spacer and mask.
• Side effects may include:
  ○ Fast heart rate
  ○ Shaking, jittery or tremors
• If your baby needs the medicine more often than every four hours, call your doctor.

Inhaled steroids
• Their common names are Flovent® (fluticasone), Pulmicort® (budesonide).
• They work by controlling and preventing swelling in the breathing tubes.
• They are given once a day through a nebulizer (breathing machine) with mask or through an MDI (pump) with spacer and mask.
• Remember to always use a spacer and a mask.
  ○ If you don’t use a spacer and a mask, the medicine will go into your baby’s mouth, not lungs.
• Side effects may include thrush- a white film on the tongue and cheeks. You can prevent thrush by rinsing your child’s mouth out after giving him or her the medicine.
• If your baby needs inhaled medicines, we will give you information about giving the medicine.

Home oxygen therapy
• Why might my baby need home oxygen therapy?
  ○ To keep his or her oxygen level normal
  ○ Some babies need oxygen all the time when they first go home
  ○ Some babies just need oxygen when feeding or at night.
  ○ To prevent high blood pressure in the lungs
  ○ To help him or her grow
• How do I give my baby oxygen?
  ○ Oxygen is usually given through a nasal cannula that fits into his or her nose and connects by tubing to an oxygen tank.
  ○ Make sure to give the exact amount your doctor prescribes.
  ○ DO NOT decrease the amount of oxygen without talking to your doctor.
  ○ If your child needs more oxygen (he or she has blue lips, desaturations on monitor, breathing difficulty), call you doctor immediately.

Breathing equipment
• Tracheostomy tubes and home ventilators
  ○ Some children with airway (wind pipe) abnormalities or who need home ventilators will have tracheostomy tubes put in place
  ○ This is done by a surgeon who will follow your child closely after he or she is sent home.
  ○ Children on ventilators are also followed by pediatric lung doctors.
  ○ We will give you information and train you if your child needs a tracheostomy tube or home ventilator.
• **Apnea monitors**
  - **Apnea** means *not breathing* and it can happen if a child isn’t trying to breathe or if something blocks the airway.
  - Apnea monitors can be used for babies who stop breathing or experience a drop in oxygen level or heart rate.
  - Apnea monitors allow you to keep track of your baby’s **breathing and heart rate** at home.
  - If your child needs an apnea monitor, we will give you information, train you and follow up with you.

• **Nutrition**
  - **Why is nutrition important?**
    - Preterm babies can have a hard time sucking and swallowing, and spend more energy feeding, leaving less energy to grow.
    - Good nutrition helps fix their injured lungs.
    - Preterm babies with CLD need extra calories to grow.
    - Before going home, we will teach you how to make the high-calorie formula and breast milk that your baby needs.
  - **Tube feedings**
    - Babies who grow poorly with mouth feeding or who choke when feeding may need a feeding tube.
    - A nasogastric (NG) feeding tube is put in the baby’s nose and ends in the stomach.
    - A surgeon puts in a gastrostomy (G-tube), and feedings go directly into the stomach or intestine.
    - If your baby needs a feeding tube, we will give you information, train you and follow up with you.

Make sure no one smokes at home
- **There is NO risk-free level of second-hand smoke.**
- **Second-hand smoke hurts your baby’s lungs, causing:**
  - Difficulty breathing
  - Increased risk of pneumonia, ear infections and other infections
  - The best way to protect your baby is to quit!
  - NOT smoking is best.
  - Quitting isn’t easy but you can get help.
    - Miriam Hospital Smoking Cessation Program 401-793-8770
    - Quit Smoking RI 1-800-QUIT-NOW or www.quitnowRI.com
  - If you or a family member can’t quit:
    - Do NOT smoke in the car or in the house.
    - Smoke outside, change your clothes and wash your hands and face when you come inside.
    - NEVER smoke around oxygen. This can cause fire.

When should I call the doctor?
- If your baby can’t stop coughing.
- If it’s hard for your baby to breathe.
  - The ribs will move in and out while breathing or the neck muscles will tighten.
  - Head moves up and down or front and back.
  - Nostrils move in and out.
  - Breathing is noisy with wheezing, grunting, severe congestion, high-pitched sounds.
  - Breathing is too fast or too slow.
- If your baby’s skin or lips are pale or blue.
- If your baby’s temperature is too cold or too hot.
- If your baby won’t eat or wake up to eat.
- If your baby vomits or has diarrhea.
- If your baby is very fussy, floppy or sleepy.
- If there are less than three wet diapers a day.

What eventually happens with CLD?
- Most babies outgrow their CLD and get better.
- Babies with CLD are followed closely by a pediatrician, pediatric lung and/or heart doctors, surgeons and other specialists.
- Most are off oxygen before their first birthday.
- CLD babies should be watched for lung infections because they get sicker faster than other children.
  - Day care may increase the risk of ER visits and infections.
- Children with CLD have an increased risk of asthma-like symptoms.