AN ALL ABOUT BPD

An Educational Booklet for Parents and Caregivers

This publication is made possible by a generous contribution from

MedImmune

CHECK Center
Children's Health System
1600 7th Avenue South
Birmingham, Alabama 35233
205-939-9377
www.chsys.org
Introduction

You have been told that your child has BPD. Our plan at Children’s Health System is to teach you what BPD is, how it’s treated, and what you can expect as your child with BPD grows.
**What is BPD?**

- BPD is short for bronchopulmonary dysplasia.

- Bronchopulmonary dysplasia describes the inside of the child’s lungs. "Broncho" means airways or tubes leading to the lungs and airspaces. "Pulmonary" means lungs. "Dysplasia" means growth that is not normal.

- BPD is a long-term lung problem (or injury) that some babies get in the first months of life. Often, it happens to babies born early whose lungs are weak, but it can occur in any baby. The oxygen and air pressure needed to keep the child alive injures and scars the lungs.

- All children grow new airways and air sacs until 8 years of age. BPD gets better over the first 2 or 3 years of a child’s life. Healthy tissue replaces scar tissue as the child grows.

- The doctor can tell which children have BPD by looking at the chest x-ray and by counting how many days the child has needed oxygen or a machine to breathe.

- Lung disease makes breathing harder. Children with BPD breathe harder than normal. Colds can make children with BPD very sick.

**Treatment Goals**

**The team goals for your child are:**

1. Teach you to safely care for your child with confidence.

2. Help with your questions, concerns, and fears about your child’s health.

3. Give your child the treatments and medicines needed to improve breathing and lung function.

4. Give enough oxygen to:
   - improve breathing,
   - prevent heart strain and
   - improve growth and development.

5. Prevent illnesses through shots and hand washing.

6. Give nutrition advice to improve growth.

7. Give activities to promote physical and mental development.

The family is part of the team!
Most children with BPD need extra oxygen for many months. Oxygen is the best "medicine" to help your child breathe better, grow, and prevent heart strain.

Why is oxygen important? Everyone needs oxygen for the body to work. Babies with BPD may need more oxygen because they work harder to breathe and because their lungs do not get oxygen into the blood easily. Normal activities like eating, crying, and playing cause your child to tire and work harder to breathe. It takes a lot of energy for a child with BPD to do these things! Oxygen helps ease breathing and prevents heart strain.

When babies do not have enough oxygen for a short time it may not harm them, they may have no immediate noticeable effect, and they may not appear different. But when oxygen level is lower for a long time, it affects the body. The heart gets larger than normal because it has to work harder to keep oxygen in the body.

Oxygen helps:
- decrease the work of breathing,
- keep the heart from working too hard, and
- the body and brain grow.

Before your child goes home, the doctors will adjust the amount of oxygen given to the lowest level possible that will still enable your child to breathe easy, eat well, and grow.
This adjustment may continue over time, since lungs get bigger and healthier as children grow. New lung tissue replaces injured parts. This process may take years. As this happens, your child may need less oxygen and the doctors will slowly lower it. Often, oxygen can be stopped in the day and used only during sleep. Oxygen during sleep is often the last therapy to be stopped.

**Oxygen Delivery Systems**
If home oxygen is needed, a home care company will give you the supplies and equipment you need. You will learn to use the equipment while rooming in. The home care company will maintain your equipment and supplies once home. They should have 24-hour service in case something breaks or you need help. If your child uses nasal cannulas, they will provide them. If your child has a tracheostomy, they will provide tracheostomy supplies, a warm moist air source, and a suction machine. You will have a source of oxygen in your home and portable oxygen for travel.

**Oxygen concentrators** plug into a wall outlet. They pull oxygen from the room, separate it from other gases, and give almost pure oxygen to your child. Concentrators are large (about the size of a kitchen trash can), but can be moved.

**Oxygen tanks** hold oxygen in gas form under high pressure. They come in many sizes. Small tanks are for travel. Small tanks often need a key to open them. You’ll need many keys. Attach one to the tank or its carrying bag. Put a key in the diaper bag, on your key ring, or in the car.

**Reading Oxygen Flow**
Oxygen flow is measured in liters per minute. All oxygen systems have a flow meter to adjust how much oxygen is given. On concentrators and tanks, there may be a tube with a ball or a readable dial that can be set to give the flow your child needs.

**Oxygen Safety**
Oxygen causes fire to burn easily and spread quickly. Oxygen should not be near open flames, cigarettes, or things that spark. Oxygen tanks are under high pressure. If the neck is broken or cracked, the tank becomes a missile. Oxygen tanks should be stored in their holders or lying flat. When driving with oxygen, secure the tanks on the floorboard. Don’t let them roll around. Don’t store them in the trunk.

**Water Bottles**
Oxygen may dry your child’s nose. Water bottles may be put on your child’s home oxygen system to add moisture to the oxygen. Do not put a water bottle on a portable oxygen tank. Portable tanks are moved and tilted and water in the oxygen tubing may drain into your child’s nose. Use distilled or sterile water to fill your water bottles.
Apnea Monitors
Apnea monitors are used to watch your child’s heart rate and breathing rate. They alarm with a high or low heart rate or if your child stops breathing for 20 seconds. The monitor is attached to your child’s chest by small patches and a Velcro belt. Check all alarms! Note what you see. If you see more alarms than usual, or if the monitor alarms when your child is warm and breathing, tell your child’s doctor and your home care company. The monitor records all use and alarms. This record can be sent to your doctor. Most insurance companies will only pay for an apnea monitor if it is used all the time.

Saturation (Sat) Monitors
A Sat monitor is used to watch heart rate and blood oxygen level. The monitor probe is often put on a toe or foot. It alarms when the blood oxygen level or heart rate drop. It can be used all the time or for quick checks. It can record use and alarms. This record can be sent to your doctor.

Travel
It takes planning to travel with oxygen and a child with BPD! You can’t take oxygen tanks on planes. You must use the plane’s oxygen. Make plans with the airline before buying your ticket. Talk to your home care company about getting supplies from another home care company in the place to which you are traveling. If you are driving a long way by car, find places on the way to refill your oxygen tanks. Your home care company can help you. Carry your child’s medicines, machines, prescriptions, and medical records with you. Talk with your doctor before planning a trip!

MEDICINES
Many children with BPD need medicines and three types are used. Bronchodilators help relax the muscles in the airways to make breathing easier and immediately help improve breathing. Anti-inflammatory medicines or steroids help decrease swelling in the airways. These medicines work over time, and they will not reverse or stop existing wheezing or distress. Diuretics help keep extra fluid off the lungs or heart. Diuretics can sometimes cause your child’s potassium or chloride in the blood to be low, so blood for lab work may be drawn in clinic to monitor this.

Some medicines have to be mixed or "compounded." Not all stores compound medicines. Sometimes it costs more. Ask your drugstore if they can compound.

ALWAYS bring the medicines your baby is taking to clinic! This table shows medicines your child may be taking:

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<tr>
<td>Flovent® Pulmicort</td>
<td>Prevents airway</td>
<td>Twice a day</td>
<td>By a nebulizer By an inhaler and spacer with mask</td>
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<td>Respules™</td>
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<td>Orapred® Prednisone</td>
<td>Lowers airway</td>
<td>Once a day</td>
<td>By mouth or feeding tube</td>
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<td>Aldactone® Diuril®</td>
<td>Prevents fluid</td>
<td>Once or twice a day</td>
<td>By mouth or feeding tube</td>
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<td>Lasix</td>
<td>build up, which makes breathing harder</td>
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<tr>
<td>Albuterol® Xopenex®</td>
<td>Relaxes airway</td>
<td>As needed for coughing, wheezing, or hard breathing</td>
<td>By a nebulizer By an inhaler and spacer with mask</td>
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<td></td>
<td>muscles, making breathing easier</td>
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<tr>
<td>Synagis®</td>
<td>Helps fight RSV</td>
<td>Once a month in winter</td>
<td>By a shot</td>
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ALWAYS bring the medicines your baby is taking to clinic! This table shows medicines your child may be taking:
NUTRITION

Growing is the key to getting better! Helping your child grow ½ - 1 ounce each day helps the lungs repair and grow. Babies with BPD usually need a special formula. They also need more calories for catch-up growth and lung healing.

Premature babies may have a hard time sucking and swallowing. This can use many calories. Premature babies also have less fat and low stores of minerals such as iron and calcium.

If you are using breast milk, your baby may need additives to increase the calories.

If you are using formula, your baby may need a premature-type formula that may be mixed differently than the instructions on the can to give more calories. BE SURE you know how to mix your baby's formula. Careless mixing can be dangerous!!

AVOID TEA, WATER, JUICES. Your baby needs only the milk. LATER, foods like cereal and fruit will be added. Your doctor will help you choose foods that will give your baby the best calories.

How can we tell if my child is growing enough?

- Get your child's weight, length, and head circumference at the doctor's office monthly for the first year.
- Ask to see your child's growth chart.
- Know what and how much your child eats! A daily food record helps the team know what nutrients your child is getting.

Feeding Problems

Some children with BPD have problems with feeding.

1. Breathing problems can cause suck and swallow problems. Use a nipple that makes sucking easier. Give short rest breaks.

2. When milk in the stomach backs up into the esophagus (tube that goes to the stomach), it is called gastroesophageal reflux (GER). Many kids have GER since the muscles that close the top of the stomach are still weak. There are medicines to treat GER, but sometimes surgery is needed. Reflux medicines include Zantac® (Ranitidine), Reglan® (Metoclopramide), Prevacid® (Lansoprazole), and Prilosec® (Omeprazole).

3. When children get food in their lungs or have poor weight gain, they may need a feeding tube to get the nutrition they need to grow. When children can't eat enough by mouth to meet their growth needs, the result is poor weight gain. Follow your child's feeding schedule! Your doctors, dieticians, and occupational therapists have looked at these factors when making your child's schedule.
Nutrition for Growth

☐ Your child should wear the oxygen as ordered by the doctor.

☐ When you mix your child’s formula, follow the directions!

☐ Tell your child’s doctor about any feeding problems your child might be having.

☐ For your toddler and young child, set regular meal and snack times.

☐ Contact the WIC office many days before you run out of formula.

My child’s formula is:

________________________________________________________________________

________________________________________________________________________

Mixing Instructions:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Feeding Schedule:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
What is WIC?

- WIC stands for Special Supplemental Nutrition Program for Women, Infants, and Children.
- The goal of the WIC Program is to improve the health and nutrition status of women, infants, and children during key times of growth and development.
- WIC gives extra foods to pregnant women, women who have just had a child, breastfeeding women, and children less than 5 years old. WIC also gives nutrition advice.
- To use the WIC program, women or children must be at nutritional risk, like having poor weight gain, and have limited income.
- The WIC Program has helped many families who have a child with BPD. Special formulas are given through WIC for eligible children with a doctor’s order. If the child with BPD is on a special formula or if the formula isn’t in local grocery stores, it can be ordered and picked up from the health department.

To use the WIC Program, your child must be certified for the program. You will need to give proof of identity, residency, and income. For example, you could bring a Medicaid card, three recent pay stubs, a copy of a benefit check, or a copy of your tax return. The WIC Program will also need a recent weight, length or height, and blood work for your child. If these were done in the hospital or at a recent clinic visit, we can send them to the WIC Program. Just ask!

✔️ AVOIDING Colds

Some children with BPD take medicine in the winter to avoid colds, like respiratory syncytial virus (RSV). This can make your child very sick. Try to prevent colds. Avoid crowded places, stay away from sick people, and have EVERYONE wash their hands. Hand washing is one of the most crucial things you can do to prevent illness.

Avoid day care, if you can. Children in day care centers share colds, ear infections, and stomach viruses easily. If you must return to work or school, try to find a day care center that only has a few babies or toddlers. You may have to visit many places and make many phone calls to find the place that is right for your child.

Respiratory Syncytial Virus (RSV)

What is it?
RSV is a lung infection. It gives most people cold symptoms, but it makes children born early and children with BPD very sick. RSV is most common in late fall to early spring.

What are the symptoms?
RSV has cold-flu symptoms, including fever and runny nose. Symptoms in some kids get worse and include coughing, breathing trouble, wheezing, and fast breathing. RSV can turn into pneumonia, and children with BPD often need more oxygen and a hospital stay.
Is it easy to catch RSV?
Yes!!! It is spread by physical contact (kissing, touching) with an infected person. The germs are also spread by sneezing and coughing. RSV can live for hours on counters, shopping carts, toys, cloth blankets, and used tissues. Exposure is common in crowded places, crowded living spaces, and day care centers. RSV can be spread by anyone -- even if they are not sick. Someone can be exposed to RSV and give it to others without knowing it.

Preventing RSV
- Wash hands before touching your child. Ask others to do so also.
- Wash hands when you first come home.
- Keep your child away from crowds of people -- especially young children.
- Keep people with colds away from your child.
- If there is smoking in the home or near the child, the risk of RSV goes up. No smoking!
- Synagis® shots once a month.

What is Synagis®?
A manmade antibody
Given as a shot once a month in RSV season

Who should get Synagis®?
According to American Academy of Pediatrics (AAP) guidelines:
- Children with serious conditions that compromise lung or immune function
- Children with BPD/chronic lung disease less than 2 years of age
- Children with heart disease less than 2 years of age
- Premature infants less than 28 weeks gestation
- Premature infants 29-32 weeks if born less than 6 months before the start of RSV season
- Premature infants 32-35 weeks if born less than 6 months before the start of RSV season and meet specific risk factors.

Know Your Child!
It is important to know how your baby acts and breathes when he is feeling well. When babies with BPD get sick, they get sicker (and sicker faster!) than babies with healthy lungs. It is important for you to know your baby’s NORMAL behavior so you can recognize when he acts or breathes differently. This also helps you be able to describe to a doctor how your baby has changed and why you are concerned.

► Behavior (How is my baby acting?)
- Is my baby acting sluggish, floppy, or sleeping through feedings?
- Is my baby becoming tired easier than usual?
- Is my baby feeding POORLY?
- Is my baby more irritable than usual?

Babies change the way they act when they are sick, starting to get sick, or when they need more oxygen.

► Breathing
- Is my baby breathing faster than usual?
  Counting breaths:
  - Look at your child’s tummy.
  - Up and down = 1 breath.
  - Put your hand lightly on your child’s tummy or chest to help you count.
  - Count breaths for 1 minute.
- Is my child coughing a lot?
- Do I hear noisy breathing like grunting or wheezing?
- Is the skin sinking in more than usual around my baby’s ribs or collarbone?
Does my child have a pale or blue color around his mouth, nose, hands, or feet?

What do you do if your baby has increased breathing distress and/or color change that does not get better with usual calming efforts?

- Check all oxygen connections.
- Check to be sure the nasal cannula is not blocked or plugged.
- Give an aerosol if available.
- Turn up your baby's oxygen.
- If your baby does not get better, call 911.

When to Call the Doctor

- Keep the phone numbers to your child’s doctor and emergency services close by. Write the numbers by your phone and carry them in a diaper bag so you (or the sitter) can call the doctor quickly, if needed. Also, keep your home address near the phone in case a sitter needs to give the location of your home in an emergency.
- Note any changes in your child’s:
  - Breathing rate
  - Cough
  - Breathing noise (grunting, wheezing)
  - Color
  - Temperature
  - Sinking in between the ribs (retractions)
  - Vomiting and/or diarrhea
  - Activity (floppy, hard to wake up, or fussy)
  - POOR feeding (not eating as much, sleeping through feeds)
  - Urine output
  - Sweating
- ALWAYS tell the doctor when you think or feel something is wrong.
Development

Many parents are excited when they get to bring their child home. Many are scared. Many are concerned about their child’s physical or mental development. With regard to your child’s development, don’t expect your child to reach developmental skills at the same rate as other babies. Your child has been sick. Your child needs time to rest and heal. BPD is a chronic lung disease. Children with BPD use extra energy to breathe. Your child may tire more easily when trying a new skill. Your child may need more time to practice crawling, walking or rolling before it’s done well.

Your child may not be doing things others are doing since your baby was born early. Children born early really have 2 ages: their real age (chronological age) and the age they would have been had they not been born early (adjusted or corrected age). If your child was born 2 months early and is now 6 months old, the adjusted age is 4 months. For the first 2 years of life, we use adjusted age in regards to development.

Like any other child, your child needs to be played with. Plan "playtimes" with your child at home. Your physical therapist may give some ideas before you go home. Here are few to try:

• Hold your child so that you are face to face. Talk to your child. Try to get your child to focus on your face as you talk.
• As kids grow, they should be able to "track" or follow a toy or your face as it moves. Toys that rattle, play music, or light stimulate hearing and vision.
• Babies should have time on their "tummies" when they are awake. They learn to lift their head and use their shoulders to push up. This practice helps with future skills like crawling and reaching for toys. Hold your child at your shoulder to practice lifting and turning his head from side to side.

Home at Last!

Prepare your baby’s crib, bed, and/or room.
• For safety, do not use pillows, rolls, or thick fluffy covers in your baby’s bed.
• Dress the baby warm enough to avoid using extra blankets.
• No toys or stuffed animals in the bed.
• Use a flat, firm mattress.
• Position your baby on his back when sleeping. It has been proven that this helps prevent SIDS (Sudden Infant Death Syndrome).
• Do not use a humidifier in your baby’s room. Too much humidity promotes the growth of allergic things like mites, cockroaches, and molds.]

KNOW CPR.
Do not permit SMOKING inside your home. Being exposed to cigar or cigarette smoke is the WORST thing for your child’s lungs. The lungs need to heal from BPD, and smoke does not let that happen. If you do smoke and can’t quit right now, always smoke outside and away from your baby.

A note: Quitting smoking is an active conscious process. It doesn’t happen overnight. It means continually reminding yourself of why you wanted to quit, of making deliberate choices NOT to smoke, and staying active and positive. Get family and friends to help you. Or, call the American Cancer Society Quit Line at 1-877-YES-QUIT (1-877-937-7848) for information about on-line and community smoking cessation classes.
Follow-Up Care

Your baby will need a community doctor and a doctor who is a lung specialist. The two doctors will work together to take care of your baby. A community doctor (or primary care doctor) is your baby’s pediatrician or family doctor. This is where your baby will get his usual baby check-ups and shots. They will also see your baby for other health problems like a fever or ear infection.

A lung specialist (pulmonary doctor or nurse practitioner) will see your baby in BPD Clinic every month or so to follow the BPD. The lung specialist will be the one to adjust the oxygen, medicines, and treatments used to treat BPD. At BPD Clinic, you will meet others on the BPD care team (nurses, dieticians, therapists, and social workers). This care team can help you with equipment, forms, and medicines. The visit to the BPD Clinic may take several hours, so bring what your baby will need during the visit (diapers, formula, and enough oxygen). Also, bring all your baby’s medicines and any records you may have. At BPD Clinic, you can expect to have your baby weighed and measured and to answer many questions about your child’s medicines, breathing patterns, activity, sleep, and feedings.

An oxygen saturation monitor will be used to measure the oxygen levels in your baby’s blood. At times, your baby will have to have lab work drawn or x-rays taken. BPD Clinic is a great time to talk about any concerns you have about your baby or to ask questions about the care. No one knows your baby as well as you, so your thoughts about your baby and your questions are very important! Some parents find it helpful to write their questions down and bring the list to BPD Clinic. Some parents bring notes they have been keeping (weights, times the baby has been sick, times the baby needed more oxygen and what was done, etc.). The pulmonary doctor will be in contact with your baby’s community doctor to let them know of your baby’s progress with BPD.

HELP

Help for Children with BPD & Their Caregivers

Financial Help

Family Assistance
- Used to be called Aid to Families of Dependent Children (AFDC)
- For people who can’t work and have no other income
- Gives some money every month for a few years or less
- In Alabama: Managed by the Department of Human Resources (DHR)
- Contact: 334-242-1950, www.dhr.state.al.us, or your DHR office

Food Stamps
- For low-income families
- In most states you can apply at the same place where you apply for Family Assistance
- Contact: 1-800-382-0499, www.dhr.state.al.us, or your DHR office

Child Support
- For unmarried parents, the parent who does not live with the child pays the parent who takes care of the child. If a parent applies for Family Assistance, the agency that processes the application will help with getting child support.
- Contact: 1-800-284-4347, www.dhr.state.al.us, or your DHR office.
Social Security

Supplemental Security Income (SSI)

- Managed by the Social Security Administration
- For people with low to middle income who are disabled, including children
- Applications can be started in person at your Social Security office or by calling 1-800-772-1213. The web site is www.ssa.gov

Social Security looks at medical problems and income to see if a child should get SSI. Even if there are big medical problems, your child can't get SSI if your income is over the limit. Give the Social Security Administration as much information as you can. You can apply for SSI at any time...even before the child comes home from the hospital.

The Social Security Administration is large! It may be hard to get a call through. It is hard and takes awhile to get benefits for your child. You might feel like giving up. No matter what you are told over the phone or in person, you have a legal right to apply on behalf of your child. Contact the social worker at your child's doctor's office if you need help.

Insurance and Other Medical Coverage

Insurance

- Usually offered by employers to employees.
- No two policies are the same.
- Children should be added right away or parents may have to wait for the next sign-up time, called "open enrollment". Sometimes you don't have to wait if the family has a big change, like one parent quitting work or parents getting divorced.

Insurance Myths

- Many people think that their child with BPD can't go on their health insurance because the child has special health care needs. Not true!
- Many think that even if a child is on their health insurance, it can't be used for 6 months or a year. Also not true!
- Some think that if a mom and dad aren't married, the child can't go on the dad's health insurance. Wrong! They can!
- In the last 10 years, many new laws have made it easier to get and keep health insurance. Your social worker can help you see if your child is eligible for your health insurance.

Important:

Many people think that if they have a job or private insurance, they can't get SSI for their child. This is not true!
COBRA
- Most employers have to let a person keep their health insurance even if they quit work.
- The employee usually has to pay more for the insurance.
- It lasts until the person gets a new job or other insurance.
- Most of the time the COBRA can be kept for 18 months, but sometimes 29 or 36 months.
- Keep COBRA if you can afford it! Staying on insurance makes it easier to get another policy in the future!
- In Alabama, if you have Medicaid and are on COBRA, Medicaid may pay the insurance premiums. Talk to your social worker.

HIPAA
- Federal law that makes getting insurance easier
- The longest period of time a person has to wait ("a pre-existing condition" waiting period) to use a new insurance policy is 12 months.
- Waiting periods are less if you have had insurance (or Medicaid) in the past. Often there is NO waiting time.
- Often a new insurance company will ask for a "certificate of coverage" to prove the person had past insurance.

Insurance issues, COBRA, and HIPAA can be confusing! Don't be scared off by terms you don't understand. Talk to your employer's benefits or human resources office until you are clear about your rights. If you don't know what to ask, talk to the Social Worker at BPD Clinic or the Financial Counselor at the Hospital.

State and Federal Programs

Medicaid
- State program to give insurance to people with low to middle income
- There are many ways to be eligible for Medicaid.
- Sometimes people with higher income can get medicaid under a "waiver".
- Medicaid has special programs to help children get the care they need like:
  - EPSDT - a screening program to make sure children get regular check-ups
  - NETS - a non-emergency transportation program that helps people pay for gas or a ride to the doctor or clinic
- Contact: 1-800-362-1504 or www.medicaid.state.al.us

SCHIP
- State Child Health Insurance Program called "ALL KIDS" in Alabama
- For children in low and middle income families who have no other health insurance
- Contact: 1-888-373-KIDS or www.adph.org/allkids

Title V (Five) Programs
- Medical and support services for children with special health care needs
- Helps find area programs
- In Alabama, the Title V program is called Children's Rehabilitation Services (CRS).
- Contact: 1-800-846-3697 or www.rehab.state.al.us
Web Sites and Phone Numbers

Web Sites

- [www.ssa.gov](http://www.ssa.gov)
  The Social Security Administration, which manages the Supplemental Security Income (SSI) program. It has a lot of disability information. You can find the nearest Social Security office with directions and maps. 1-800-772-1213

- [www.insurekidsnow.gov](http://www.insurekidsnow.gov)
  Sponsored by the Department of Health and Human Services. It has links to all State Child Health Insurance Programs (SCHIP). 1-877-kids-now

- [www.cms.hhs.gov](http://www.cms.hhs.gov)
  The Centers for Medicare and Medicaid Services (CMS), formerly the Health Care Financing Administration (HCFA). This federal agency manages Medicaid and SCHIP.

- [www.familyvoices.org](http://www.familyvoices.org)
  Family Voices is a group of parents and other people concerned with the care of children with special health care needs. It has a lot of caregiver information on how to stand up for your child’s needs and how to find programs for your child. 1-888-835-5669

- [www.mchb.hsa.gov/programs](http://www.mchb.hsa.gov/programs)
  This link, on the Maternal and Child Health Bureau web site, has information on every state's Title V program for children with special health care needs.

- [www.nhlbi.nih.gov](http://www.nhlbi.nih.gov)
  The National Heart, Lung, and Blood Institute (NHLBI) gives information to health care staff, patients, and the public about the treatment, diagnosis, and prevention of heart, lung, and blood diseases.

Phone Number

- Child Find 1-800-543-3098
Years ago, children needing oxygen stayed in the hospital. Today, parents can take care of their child on oxygen at home. In fact, research shows that babies grow and develop much faster at home with families.

Children grow at the fastest rate in the first two years of life. Your attention, time, and patience will pay off! You will love seeing your child smile, coo, cuddle, and reach for a toy. Your child may still need physical or occupational therapy at home. You might see private local therapists or be referred to an Early Intervention program. All of this will be arranged and explained before you leave the hospital or in clinic.

Caring for a child with BPD can be hard and scary. But with hard work, persistence, and family commitment, you can do it. You can make a difference in your child’s life!

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Oxygen

Nutrition

NOTES

Not all babies with BPD need the same BPD plan. The doctor or nurse will check your baby and listen to you to decide about the plan of care. Always discuss the plan with your child’s lung specialist and/or community doctor before making any changes.