



Children's  
of Alabama®

# all about BPD



An educational booklet for Parents and Caregivers



# Table of Contents

What is BPD? .....	4
Treatment Goals .....	5
Treating BPD .....	6
Oxygen .....	7
Medicines .....	11
Nutrition .....	12
Avoiding Colds .....	16
Know your child .....	18
When to call the Doctor .....	19
Development .....	19
Early Intervention .....	20
Home at Last .....	21
Follow-up Care.....	22
Help.....	23
Web Sites and Phone Numbers .....	26
Summary .....	28
Schedule for Medicines/Notes.....	29

# INTRODUCTION

The long awaited day is just around the corner and you will soon be taking your baby home from the NICU. You are probably feeling a mixture of emotions that include joy, anxiety and apprehension. The more education you receive about caring for your baby the less anxious you will become. This booklet reviews the key points in caring for a child with BPD in the home setting. This book is designed to help with your BPD discharge education, and to serve as a quick reference after your baby is discharged. Please remember that every child is unique and every question is an important one. Do not hesitate to contact your lung doctor should you have any concerns or questions.

## 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, also known as chronic lung disease of infancy, is a long-term problem (or injury) that some babies get in the first months of life. Often it happens to babies born early whose lungs are weak and not fully developed, but it can occur in any baby.
- BPD gets better over the first 2 or 3 years of a child's life. Healthy tissue replaces scar tissue as the child grows, so the child's growth is very important.
- 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 hard. Children with BPD breathe harder than normal. Colds can make children with BPD very sick.

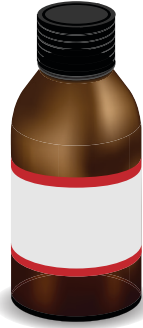
## Treatment Goals

The treatment goals for your child are to:

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 immunizations and handwashing.
6. Give nutritional advice to improve growth.
7. Encourage activities to promote physical and mental development.

The family is part of the team!

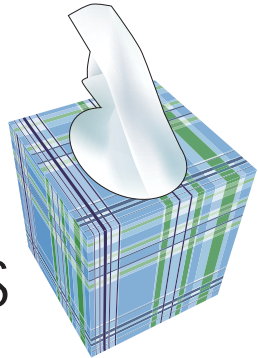
Treating BPD



MEDICINES



NUTRITION



AVOID COLDS



DOCTOR'S VISITS



HELP

# OXYGEN

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 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 the oxygen level is low for an extended period of time it does affect the baby. 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 make sure the amount of oxygen your baby is getting is the lowest amount needed that will still help your child to breathe easy, eat well, and grow.

You will be taught how to adjust the flow meter. It is important to follow the doctor’s instructions about when to change the flow. Do not make changes without the doctor’s instruction.

As your child gets older, the lungs will get bigger. New lung tissue replaces injured parts. This process may take many months. 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 equipment while rooming in, before you go home.

The home care company will:

- Maintain your equipment and supplies when home.
- Provide 24-hour service in case something breaks or you need help.
- Provide a source of oxygen in your home and portable oxygen for travel.
- Provide education for care providers about equipment use.
- If your child has 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.

**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. Some children will require  $\frac{1}{4}$  to  $\frac{1}{2}$  liters per minute (Lpm) more on concentrator than on oxygen tanks. Concentrators are large (about the size of a kitchen trash can), but can be easily moved.

**Oxygen tanks** hold oxygen in gas form under high pressure. The tanks come in many sizes and are for use when away from the home concentrator or when there is a power outage. Insurance companies pay for a limited number of portable tanks per month to be used for medical appointments and therapy. It is very important to save these tanks for these appointments.

Small tanks are for patients that need a lower liter flow of oxygen. Small tanks often need a key to open them. You will need many extra 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 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. Use distilled or sterile water to fill your water bottles.

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.

## Monitors

The purpose of monitors is to alert the parent to assess the child. Do Not Panic! There are many factors that can affect why the monitor alarms. These factors include movement, disconnected probes and distress.

### **Saturation (sat) Monitors**

A sat monitor is used to watch heart rate and blood oxygen levels. The monitor probe is often put on a toe or foot. The monitor will alarm when the blood oxygen level (saturation) or heart rate drop. It can be used all

the time or for quick checks, depending on what the doctor orders. It can record use and alarms. This record can be sent to your doctor.

At the time of discharge, we want to be sure the saturation levels do not go too low. If there is not enough oxygen in the body, the heart and brain may be affected. The doctor will tell you what the saturation level should be now that your child is older.

### **Apnea Monitors**

Apnea monitors are used to watch your child's heart rate and breathing rate. The monitor is attached to your child's chest by small patches and a Velcro belt.

The monitor will alarm with a high or low heart rate or if your child stops breathing for 20 seconds. Check 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.

### **Travel**

To travel with a child with BPD and with oxygen, you must make plans!

**Air Travel:** You can't take oxygen tanks on planes. You must use the plane's oxygen. Make plans with the airline before buying your ticket.

**Trip Plans:** Talk to your home care company about getting supplies from another home care company in the place you are traveling to.

If you are driving a long way by car, find places on the way that will 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 several types are used.

**Bronchodilators** help relax the muscles in the airways to make breathing easier and immediately help 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 drugstores compound medicines and sometimes it costs more. Ask your drugstore if they can compound, if not ask the pharmacist to help you choose a drugstore before discharge. **It is important to choose one drugstore and use it for all the child's prescriptions.**

When the medication begins to run out you will return to this same drugstore for refills. Call the drugstore two days before you will need the medicine to give them time to mix the medicine. Do not let medications run out, this can be dangerous for children with BPD. Never stop any medications before talking with your child's doctor.

**ALWAYS** bring your child's medicine or a cell phone photo of the current prescriptions label with you to clinic.

What?	Why?	When?	How?
Flovent® Pulmicort Respules™	Prevents airway swelling	Twice a day	By an inhaler and spacer with mask By a nebulizer
Orapred® Prednisone	Decreases airway swelling	Once a day	By mouth or feeding tube
Aldactone® Diuril® Lasix	Prevents fluid build up, which makes breathing harder	Once or twice a day	By mouth or feeding tube
Albuterol® Xopenex®	Relaxes airway muscles, making breathing easier	As needed for coughing, wheezing, or hard breathing	By a nebulizer By an inhaler and spacer with mask
Synagis®	Helps fight RSV	Once a month in winter	By a shot
Sildenafil	Dilates blood vessels to improve blood flow to heart and lungs	Several times daily	By mouth or feeding tube

# NUTRITION

Growing is the key to getting better! Helping your child grow each day (20-30 grams or ½ to 1 ounce a 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 a lot of calories. Premature babies also have less fat and low 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 and it may be mixed differently than the instructions on the can to provide increased calories. If your baby requires more calories you will be given special mixing instructions at the time of discharge.

**BE SURE** you know how to mix your baby's formula. *Mixing incorrectly can be dangerous!!*

**DO NOT GIVE TEA, WATER, or JUICES to your baby. Your baby needs ONLY the formula.**

Later, foods like infant cereal and baby foods will be added. Your doctor will tell you when it is ok to start foods and will help you choose foods that will give your baby the best calories and nutrients.

## **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.

- Breathing problems can cause suck and swallow problems. Use a nipple that makes sucking easier. Give short breaks during feeding if needed.
- The tube that goes from the mouth to the stomach is called the esophagus. When the formula in the stomach backs up into the esophagus, 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.
- When children can't get enough by mouth to meet their growth needs, the result is poor weight gain and the lungs can't heal and grow as needed.
- When a child has poor weight gain, they may need a feeding tube to get the nutrition they need to grow.
- Follow your child's feeding schedule!
- Your doctors, dieticians, and occupational therapists have looked at all of your child's needs when making your child's feeding schedule.

# Ensuring Growth

- Your child should use oxygen as ordered by the doctor.
- When you mix your child's formula, follow the directions given by the nutritionist.
- 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 your run out of formula.



## 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, breastfeeding women, women who have just had a child, 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.
- WIC is a supplemental program and will most likely not provide 100% of formula needs.
- 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 also will 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 viruses, like respiratory syncytial virus (RSV). This virus can make your child very sick.

- Try to prevent colds.
  - Babies with BPD that get colds can become so sick they may need to be readmitted to the hospital.
- Avoid crowded places
- Stay away from sick people
- 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 daycare centers share illnesses easily.
  - If you must return to work or school, try to find a daycare 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.
- Be sure your child receives Synagis® vaccine from your pediatrician monthly during RSV season (Oct-March)

## 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?

- Cold/flu symptoms, including fever and runny nose.
- Symptoms in some children get worse and include coughing, breathing trouble, wheezing, and fast breathing.
- RSV can turn into pneumonia, and children with BPD will often need more oxygen and a hospital stay.

### Is it easy to catch RSV?

- Yes!!!! It is spread by physical contact (touching, kissing) 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 daycare 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 this 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 (October to March).

### **What is Synagis ®**

- A manmade antibody. An antibody fights infection in the body.
- Given as a shot once a month in RSV season (October to March).

### **Who should get Synagis ®**

According to the American Academy of Pediatrics (AAP) guidelines:

- Children with serious conditions that compromise lung or immune function
- Children with BPD or chronic lung disease less than 2 years of age
- Children with heart disease less than 2 years of age
- Premature infants less than 29 weeks gestation
- Premature infants 29-32 weeks with BPD

# 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 will know when he/she acts or breathes differently. This will also help 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 or floppy, or sleeping through his 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?

## Color

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 the baby's oxygen. (If improves notify lung doctor that child is needing more oxygen to keep saturation levels within the acceptable range)
- 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 your 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.

Call your lung doctor if you notice 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 level (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 and some are concerned about their child's physical or mental development. Don't expect your child to reach developmental skills at the same rate as other babies. Your child has been sick and needs time to rest and heal.

BPD is a chronic lung disease. Children with BPD use extra energy to breathe and may tire more easily when trying a new skill. Your child may need more time to practice crawling, walking or rolling.

Your child may not be doing things others are doing since your baby was born early. Children born early really have 2 ages:

- Real age (chronological age)
- 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 and growth.

Your child needs to be played with, like any other child. Plan “playtimes” with your child at home. Your physical therapist may give some ideas before you go home. Here are a 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 children grow, they should be able to “track” or follow a toy or your face as it moves. Toys that rattle, play music, or light up 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. **Do NOT leave your child on their tummy to sleep or if you are not with them!!**
- Hold your child at your shoulder to practice lifting and turning his head from side to side.

## Early Intervention

- Babies who are at risk for developmental problems might need help to catch up.
- Early Intervention is a program that can provide therapy and other help for babies who need this kind of help.
- Different agencies provide the programs and have different names depending on where you live.
- The federal government calls all these programs “Part C” programs.
- Be sure to ask before taking your baby home from NICU if Early Intervention is needed. You can always ask your pediatrician or BPD doctor too.
- The National Early Childhood Technical Assistance Center (NECTAC) web site has contact information for the Part C programs in every state: <http://www.nectac.org>.
- Alabama’s Early Intervention System (AEIS) can be found at [www.rehab.alabama.gov](http://www.rehab.alabama.gov), or by calling Child Find at 1-800-543-3098.

## Home at Last!

Prepare your baby's crib, bed and/or room.

- For safety, do not use pillows, rolls, bumper pads 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.
- Do not use a humidifier in your baby's room. Too much humidity promotes the growth of allergic things like dust mites, cockroaches, and molds.
- Use a flat, firm mattress.
- Always put your baby on his or her back when sleeping. It has been proven that this helps prevent SIDS (Sudden Infant Death Syndrome).
- Always follow the ABC's of putting your baby to bed... Alone, Back, and Crib unless instructed otherwise by your physician.
- **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. Especially avoid smoking in the car.

A note: Quitting smoking is an active, conscious process. It does not happen overnight. It means you must continually remind yourself of why you wanted to quit, of making the choice NOT to smoke, and staying active and positive. Get family and friends to help you.

Call the Alabama Tobacco Quit Line at 1-800-Quit-Now (1-800-784-8669) for information about on-line or community smoking cessation classes.

## Follow-Up Care

Your baby will need a doctor near you in your community and a doctor who is a lung specialist. The 2 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 have regular 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, nutritional plan and treatments used to treat BPD.

At BPD Clinic you will get to know others on the BPD care team (nurses, dietitians, therapists, and social workers). This care team can help you with equipment, forms and medicine. The visit to the BPD Clinic will take several hours, so remember to bring what your baby will need during the visit (diapers, formula, enough oxygen). Also bring all your baby's medicines and any records you may have. If your baby's name has been changed, bring the birth certificate with you.

At BPD Clinic, you can expect to have your baby weighed and measured and to answer lots of questions about your child's medicines, breathing patterns, activity, sleep, and feedings.

- Your baby may need to have blood work done or x-rays taken.
- BPD Clinic is the time to talk about any concerns you have about your baby or to ask questions about the care.
- 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 pediatrician to let them know of your baby's progress with BPD.

# HELP

## Help for Children with BPD and Their Caregivers

### Financial Help

Temporary Aid to Needy Families (TANF) or Family Assistance (FA)

- Used to be called Aid to Families of Dependent Children (AFDC)
- For people who can't work and have no other income
- Can provide cash payments and job training
- 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.alabama.gov](http://www.dhr.alabama.gov) or your DHR office

Supplemental Nutrition Assistance Program (SNAP)

- Used to be called Food Stamps
- For low-income families
- In most states, you can apply at the same place where you apply for FA
- Contact: 1-800-242-1700, [www.dhr.alabama.gov](http://www.dhr.alabama.gov), 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 FA, the agency that processes the application will help with getting their child support.
- Contact: 1-800-242-9300, [www.dhr.alabama.gov](http://www.dhr.alabama.gov), 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](http://www.ssa.gov)

**Important:**  
Many people think that if they have a job or private insurance they can't get SSI or Medicaid for their child. This is not true!

Social Security looks at medical problems and income to see if a child should get SSI. Low birth weight is a medical problem that may qualify your baby for 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!
- Recently, 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.

## 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.

## AFFORDABLE CARE ACT (ACA)

- Babies with BPD need healthy parents – think about health insurance for you, too.
- Starting in 2014, more people will be able to get health insurance through the “Marketplace.”
- People who were turned down for individual health insurance in the past can now get coverage. It is not free, but sometimes tax credits are available.
- More information can be found at [www.healthcare.gov](http://www.healthcare.gov), or by calling 1-800-318-2596. Ask at BPD Clinic if you need help.

Insurance issues, COBRA, and the ACA 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 a lot of 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.alabama.gov](http://www.medicaid.alabama.gov)
- Medicaid can pay for birth control for moms, too. This is called the “Plan First” program. Information is on the Medicaid web site or at 1-888-737-2083.

## 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 (1-888-373-5437) or [www.adph.org/allkids](http://www.adph.org/allkids)

You can start an application online for some types of Medicaid, Plan First, and ALL KIDS at [www.insurealabama.org](http://www.insurealabama.org)

## Title V (Five) Programs

- Medical and support services for children with special health care needs
- In Alabama, the Title V program is called Children’s Rehabilitation Services (CRS)
- Contact: 1-800-441-7607 or [www.rehab.alabama.gov](http://www.rehab.alabama.gov)

## 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). Contact: 1-877-KIDS-NOW (1-877-543-7669)
- [www.familyvoicesal.org](http://www.familyvoicesal.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.

The Alabama Family-to-Family Health Information Center, part of Family Voices, can also provide training for parents who want to help other families, and match families to mentors.

Contact: 1-877-771-FVOA (1-877-771-3862)

You can also order a “Care Notebook” to keep track of your child’s appointments, tests, and progress.

- [www.mchb.hrsa.gov](http://www.mchb.hrsa.gov)

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.

- <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.

## Summary

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!

Medicine	How to Give	Time(s)
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

Oxygen: \_\_\_\_\_

Weight at Discharge: \_\_\_\_\_

Nutrition: \_\_\_\_\_

Not all babies with BPD need the same BPD plan. The doctor or nurse will check with 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.

NOTES: \_\_\_\_\_

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