



BPD and Me

A guide to manage
bronchopulmonary dysplasia



Riley Children's Health
Indiana University Health

rileychildrens.org

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Introduction

Congratulations. It's finally time to leave the neonatal intensive care unit (NICU). Going home after a long stay in the NICU is exciting but can cause some anxiety as well. This guide will serve as a quick reference to help you feel more comfortable with your child's care.

- Your child has been scheduled to follow up in the BPD (bronchopulmonary dysplasia) Clinic. This multidisciplinary specialty clinic will help guide your child's care now that you have left the NICU.
- Our goal is to partner with you, your pediatrician and any other specialists to provide your child the best medical care available.

The BPD Clinic specializes in treating babies with bronchopulmonary dysplasia or lung disease associated with preterm birth.

This clinic consists of multiple specialists with special expertise in the care of premature babies. In our clinic you will see the following specialists:

1. Pulmonary specialist
2. Early years provider
3. Registered dietitian
4. Speech therapist
5. Physical therapist
6. Respiratory therapist
7. Social worker
8. Registered nurse



You may not see every provider at each visit. We will tailor your child's care to their needs. We will see you at frequent intervals and gradually space out appointments to meet your child's individual needs.



What is BPD?

BPD is short for bronchopulmonary dysplasia. Bronchopulmonary dysplasia is the medical term for lung disease associated with preterm birth.

When babies are born prematurely, their lungs are not fully developed. The ventilator and oxygen support needed to help a premature infant survive in the NICU can cause further damage to their already fragile lungs. The severity of lung disease is different for every baby. Some babies will leave the NICU without any additional respiratory support, while other babies may require home oxygen or tracheostomy.

- BPD is diagnosed in the NICU. Doctors will determine if your child has BPD by the level of respiratory support at different times. BPD can be classified as mild, moderate or severe.
- Infants with BPD require specialty care after leaving the NICU. Infants with BPD often struggle to breathe, eat by mouth and grow even after leaving the NICU. Your baby will require care by medically trained specialists to create an individualized plan for your infant.
- Infants with BPD may require medications or therapies at home. Your child's medical team will determine what specialty care is going to be required at home. You will be given education prior to leaving the NICU on what your home regimen will be.
- Most children with BPD improve over time. As your baby grows, their lungs continue to grow as well. As new lung tissue is formed, respiratory symptoms gradually improve. This may take several months or years.



Treatment goals

The treatment goals for your child are:

- **To help you feel comfortable with your child's care at home.** Infants with BPD may require supplemental oxygen, medications, breathing treatments, feeding tubes and/or special formula. All of these things can be overwhelming. Our goal is to make sure you receive the education and tools you need to be successful at home.
- **To provide the medicine and treatments to help your child thrive.** Your child may require medications and treatments to treat their BPD. Our team will manage these medications and ensure your child is getting enough oxygen to grow and heal at home.
- **To provide a feeding regimen that will help your child grow.** Infants with BPD often spend extra calories breathing. This can make it difficult for them to grow. Our dietitian and early years provider will work together with the lung doctor to make sure your baby is getting enough calories to grow and help heal their lung disease.
- **To set your child up with early intervention to help with delays associated with prematurity.** Being born early makes it more likely that a baby will have developmental delays. Being diagnosed with BPD further increases the risk for delays. Setting your child up for early intervention therapy can help your baby catch up. Our early years medical provider along with our therapists will determine what your child needs. We can set up therapy in the home through First Steps or schedule therapy at an outpatient clinic if you prefer. Many babies with BPD benefit from therapy in both places.
- Remember, until your baby's second birthday, we "adjust" or "correct" for their prematurity. As an example, if your baby was born three months early, we would give them the benefit of an extra three months with their developmental and feeding skills. So when your baby is 6 months old, we would only expect them to have the developmental and feeding skills of a typical 3 month old.
- Our goal is to have your baby "caught up" by the time they turn 2 years old, so that they can get ready to enter school with kids their own age.



Oxygen

Everyone needs oxygen to survive. Babies with BPD may need extra oxygen due to their lung disease. BPD makes it more difficult for the lungs to do their job. Activities like eating, playing and crying can cause your baby to work harder to breathe.

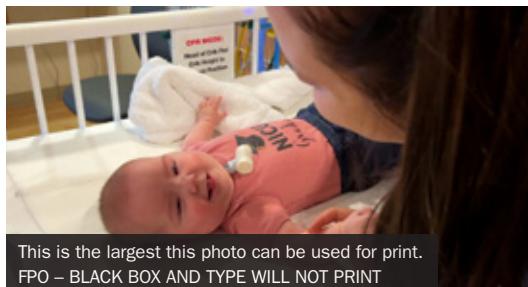
Supplemental (extra) oxygen can help make these things easier. Oxygen may be provided by nasal cannula or heated humidity given through a tracheostomy (trach) collar. Important information about going home on oxygen:

▪ **Oxygen is prescribed by your physician.** Your child is sent home on the lowest amount of oxygen needed to keep your baby healthy. Do not lower the amount of oxygen or stop using it without talking to your lung doctor first. Low oxygen levels can put extra strain on the heart. We will lower the amount of oxygen at clinic visits when indicated.

▪ **You will monitor your baby's oxygen.** You will be sent home with a pulse oximeter if your baby goes home on oxygen. Your home care vendor will train you on how to use it. It is important to use the pulse oximeter to monitor your infant's oxygen and heart rate levels. You will need to move the sensor every four hours to prevent injury and burns. You can do this with diaper changes or feedings to help you remember. If your monitor is alarming with low oxygen levels, high or low heart rate, you will need to troubleshoot possible causes.

1. Is the monitor secured to the foot properly? Are the cords attached?
2. Is your child quiet and still or kicking and screaming? If your baby is moving the monitor may not be giving an accurate reading.
3. If the monitor continues to alarm and it is secured properly and picking up well, check your oxygen equipment. Is the nasal cannula in and attached to the tank or concentrator? Is the tank or concentrator set to the correct setting?
4. If the monitor continues to alarm call your doctor.

▪ **A home care company will provide you the supplies you need.** Before leaving the hospital you will be assigned a home care vendor. This vendor will supply you with all of your oxygen and monitor supplies. Make sure you save the number in your phone or put it somewhere handy. If you are in need of supplies or if your equipment is not functioning correctly, call them. If you are not getting the supplies you need despite calling your vendor, please call the BPD Clinic at **317.948.7208** so we can help.



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Medications

Your doctor may prescribe medications to treat BPD at home. It is important to give these medications as instructed. The following are commonly prescribed medications. Your child may be prescribed one or some of these.

▪ **Inhaled steroids.** These medications are given every day, two times a day. They can be given through a nebulizer or inhaler. Inhaled steroids help prevent swelling of the airways.

▪ **Bronchodilator.** These medications are given as needed. Usually, they are given when a child is sick. They can be given through a nebulizer or inhaler. Bronchodilators are used to relax and open the airway.

▪ **Oral steroid.** These are given for acute illness. A short course of oral steroids can help decrease swelling in the lungs.

Your baby may be going home on medications to treat other conditions. It is important to know who to call if you have questions or need a refill. Make sure to discuss this with your pediatrician if you are unsure.



Feeding and nutrition

One of the most important jobs for premature babies is to grow. Growing indicates healing, which is how they get better. On average, premature babies need to gain about an ounce a day for the first few months after NICU discharge to ensure they stay on their growth curve and to make sure their lungs are healing. In the BPD Clinic, you will work with the early years medical provider, registered dietitian and a speech language pathologist (SLP), who is an expert in helping babies eat safely.

Babies with BPD can have difficulty feeding because their breathing pattern can affect how they suck and swallow from the bottle or breast. Babies with BPD are more likely to have problems with aspiration, which is when some breastmilk or formula goes into their breathing tube and lungs instead of into their stomach. This can cause further damage to lungs that already are hurt by BPD. It is important to watch for any signs of aspiration including coughing, choking, gagging, watery eyes, facial redness or increased congestion during feeding.

On average, premature babies need to gain about an ounce a day for the first few months.

Bottles/Nipples

In the NICU, your baby's medical team carefully selected a bottle and nipple that keeps your baby's breathing and feeding the safest. It is important to stay on that same nipple until you see our feeding team in the BPD Clinic. If you are worried that your baby's nipple is too fast or too slow—or if you need help finding more of the nipple that you were given—please reach out to us before your first appointment.

When a child cannot eat safely or enough by mouth, they may need a feeding tube to get the nutrition they need to grow. A tube that goes through the nose is called a nasogastric (NG) tube and a tube that goes through the stomach is called a gastric (G) tube.

If your baby has a feeding tube, you will work with the medical provider, an SLP and dietitian to wean them off as they are ready. Your baby may need a swallowing test before we can stop using their feeding tube. It can be harmful to stop tube feeds too early, and it may cause delays to your baby's long-term feeding progress.

Breastmilk/Formula

Premature babies need extra calories to grow due to them burning extra calories to work on breathing and feeding. This means you may have to mix your baby's formula differently from the recipe on the formula can. If you breastfeed your baby, you may need to add formula to your breastmilk to increase the calories in it to make sure your baby gets the calories they need.

MIXING INCORRECTLY CAN BE DANGEROUS. Be sure you are following the recipe given to you by the dietitian at discharge. The recipe on the back of the formula can is not always the same as the recipe your baby was sent home on. If you have questions regarding what recipe you should be following, call the BPD Clinic.

There are special formulas for premature babies that have more nutrients in them that help with your baby's growth and development. Sometimes premature babies need even more and will be put on supplements such as a multivitamin, vitamin D, iron, calcium, etc.

As your baby grows, they will need more calories to accommodate their growth patterns. It is recommended to increase the volume of feeds by 5 mL weekly to ensure your baby is getting enough formula or breastmilk. If your baby is on a continuous feed, it is recommended that you increase the pump rate by 1 – 2 mL per hour weekly and add that volume to the batch. The hospital should send you home with an advancement plan to follow until your first BPD appointment, but if you have any questions before that appointment, call us at **317.948.7208**.

Baby food

Later in your baby's first year, they will be introduced to baby foods and other infant-friendly snacks. Your doctor or SLP will let you know when it is safe for your baby to start these. We do not recommend adding cereal to bottles unless directed by an SLP.

It is important to follow all feeding recommendations given to you by your team. These recommendations are given to keep your baby safe and healthy.



Physical therapy

Importance of early intervention through physical therapy:

- Physical therapists (PTs) can help your baby with their movement skills. They are the therapists who can help your baby roll over, sit up, crawl, stand and run. They will help us keep track of important developmental milestones and make sure your baby is developmentally typically.
- In babies with BPD, PTs can also help you learn exercises and positions to help support your baby's diaphragm, which is a big muscle that controls breathing.
- For all babies in the NICU, PTs can help with positioning to help prevent head flattening.

Things to do with your baby after being discharged from the NICU:

- Tummy time, tummy time, tummy time. This is the most important thing you can do with your baby at home. Try to get in several sessions of tummy time a day when your baby is awake. They don't have to be for very long—even 5 minutes at a time is great to start. Your baby will be able to do longer times with practice.
- You can also put your baby lying on their side while they are awake and you are supervising. This allows them to explore toys and look around in a different way.
- Your baby should spend lots of time when they are awake on the floor. Babies learn how to move and explore their environment best on the floor. If you have hard floors at home, you can spread a blanket or quilt out on the floor.
- You can show black and white images to your baby. Allow your baby to look at the image, then move it side to side slowly to help with tracking. Your black and white image doesn't need to be fancy—you can draw a big smiley face with a black marker on white paper.
- When your baby is in a car seat, pay attention to which way their head looks. Ideally, we want a baby's head to be in the middle, not always looking to the left or the right. If you notice that your baby is always looking to one side, or has their head tilted in one direction, please let us know.



**Tummy time
is the most
important thing you
can do with your
baby at home.**

What is First Steps:

- First Steps is a program in Indiana that provides developmental support to children from birth – 3 years of age.
- First Steps provides therapists to provide therapy in your home at free or reduced cost, depending on your income.
- First Steps can provide therapists to support gross motor (big muscle) skills, fine motor (small muscle) skills, feeding skills, communication skills, play skills, vision and hearing.
- Most babies with BPD would benefit from First Steps involvement.
- Once you are referred to First Steps, you will have an intake call, followed by an evaluation. If you qualify for services, First Steps will help find a therapist to treat your baby.
- For more information about First Steps, please ask your BPD team.

First Steps is not the right fit for every family. If you are interested in outpatient therapy instead of home-based therapy, please let us know so we can make the necessary referrals.



Developmental testing

While your baby is followed in the BPD program, they will receive screening for neurodevelopmental conditions that are more common in babies born prematurely.

These include:

Cerebral palsy – Cerebral palsy is the most common physical disability of childhood and affects 1 in 500 children in the US. One in 10 children born at less than 28 weeks develop cerebral palsy, which is a disorder in how muscles function. Cerebral palsy is a spectrum of disease, meaning that there is a wide range in how children are affected.

- Your baby will have tests done at 3 – 4 months adjusted age, including a video (General Movements Assessment) and neurological exam (Hammersmith Infant Neurological Examination). These tests, in addition to information from your child's NICU stay, can allow the medical team to tell early if your baby is at higher risk for being diagnosed with cerebral palsy.

Autism spectrum disorder – Autism is a spectrum of conditions that can present challenges in the way individuals communicate and interact with others. It is also more common in children born prematurely.

- Around 18 months adjusted age, you will be given a screener to fill out that tells us if your child is at low, medium or high risk of being diagnosed with autism. If your child is at medium or high risk, we can schedule a virtual appointment with a developmental psychologist who can do further testing, if needed. Our goal is to diagnose autism spectrum disorders early (as toddlers) to help families access extra services, if needed.

Developmental delays

- Developmental delays refer to any delays in your child's developmental skills, including their movements (e.g., delayed sitting, crawling), their play skills (difficulty pushing buttons on toys) or their communication (delays in speaking, communicating).
- At many of your visits, you will fill out a developmental screener. Before the age of 2 years, we will adjust this screener for your child's prematurity.
- You will also visit with some of our therapists at visits, who can also screen for delays.
- At age 2 years, your child will be referred for a thorough developmental test called the Bayley Evaluation. This is done by a developmental psychologist and/or a physical or occupational therapist. This will give a full picture of your child's development, including early cognitive (thinking) skills.



Family support

Our social worker is available while you are at your appointment or by phone. Social workers can assist families with financial resources, community programs and mental health support. If you have any questions about transportation, insurance or barriers to caring for your child, reach out to our social worker. Most of these resources are available only for Indiana residents. If you live in another state please reach out for options in your state.

Resources

Mental health

During your visit, parents may be asked to fill out the Edinburgh Postnatal Depression Scale. The 10-question scale is a valuable and efficient way of identifying postnatal depression. Your social worker will then review your score and provide resources if necessary.

Postpartum resources

- PSI HelpLine: [800.944.4773](tel:800.944.4773) (call or text "Help")
- Online support groups: postpartum.net/get-help/psi-online-support-meetings/
- Find a provider: postpartum.net/get-help/locations/

Early Years Mental Health Program

Our early years clinical psychologists are available to provide mental health services for the Riley Early Years Program.

- Support related to parenting young children with medical needs, challenging behaviors or social emotional concerns
- Treatment focused on parental anxiety, depression, trauma or loss that may impact parenting or the parent-child relationship
- Assessment of developmental delays and/or autism spectrum disorder

Telehealth (virtual) psychology services are billed to the child's insurance company, and visits are documented in the child's IU Health medical record. Please don't hesitate to ask if you have questions about billing and documentation.

Community Mental Health

Adult and Child Mental Health

- Accepts Medicaid and some private insurance
- Locations around Central Indiana
- Contact: [877.882.5122](tel:877.882.5122)

Cummins

- Accepts Medicaid and some private insurance
- Locations around Central Indiana
- Contact: [888.714.1927](tel:888.714.1927)

Aspire

- Accepts Medicaid
- Locations around Indianapolis area
- Contact: [877.574.1254](tel:877.574.1254)

Help for Children with BPD and their caregivers

Programs

Community partners

- Referral services for counseling, housing, food and clothing assistance, employment and other social services
- Financial assistance for counseling and short-term, emergency problems
- Goal setting through case management in the home or at a neighborhood location most convenient to the family
- Ask a social worker for a referral if you're interested

Community Compass

- Provides a list of local pantries, WIC retailers and free meals
- communitycompass.app

Indiana Family to Family

- Aids families and professionals navigating healthcare systems
- Gives information, education, training, support and referral services
- Guidance on health programs and policies
- inf2f.org
- Contact: 844.323.4636

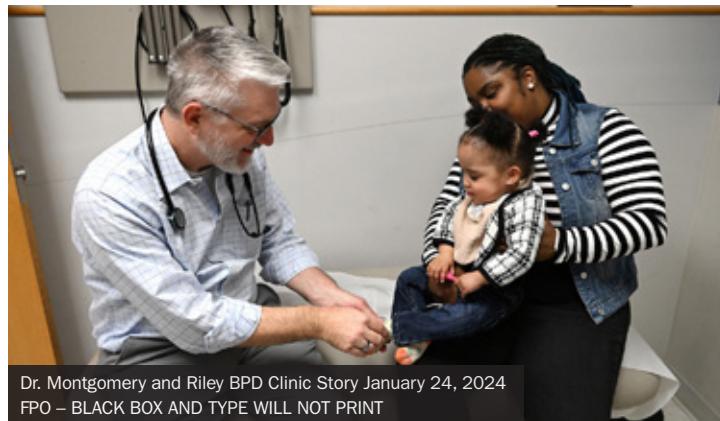
Medicaid waivers

Aged and disabled waiver

- Child must be medically fragile (g-tube, trach, vent, etc.)
- May provide caregiver pay, case management, healthcare coordination, respite, etc.
- Contact: 800.986.3505

Family supports waiver

- Child must be developmentally disabled
- May cover various specialty therapies (e.g., music, recreational, occupational, psychological), respite, behavioral intervention, caregiver training, etc.
- Contact: 800.545.7763



Dr. Montgomery and Riley BPD Clinic Story January 24, 2024
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Financial help

WIC (Women, Infants, and Children)

- Nutrition program that helps pregnant women, new mothers, infants and children
- Used at stores to purchase nutrient dense food (fruits, veggies, baby food, protein, etc.)
- in.gov/health/wic

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

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: 800.242.1700
- fssabenefits.in.gov

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 800.772.1213
- ssa.gov



Who do I call?

Riley BPD Clinic

Monday – Friday, 8 am – 4:30 pm:
317.948.7208

After hours and weekends:
317.944.5000
Ask to page the Riley Pulmonary doctor on-call

What if my child is healthy and needs:	Pediatrician	BPD Clinic	Other
Well-child check-up	X		
Immunizations	X		
Flu shot	X		
RSV prevention	X		
BPD check-up		X	

What if my child is sick and:	Pediatrician	BPD Clinic	Other
Has a runny nose or congestion	X		
Has wheezing or difficulty breathing		X	
Has low oxygen saturation		X	
Has a cough		X	
Has trach issues		X	
Has a fever	X		
Has a rash	X		
Is vomiting: Sudden onset?	X		Please note if your child has a shunt: Call neurosurgery at 317.944.6201
Is vomiting: Continued trouble tolerating feeds?		X	
Has constipation	X		
Has diarrhea	X		
GT site irritation			Surgery clinic at 317.944.4681 or GT nurse 317.944.5018

What if I have questions about:	Pediatrician	BPD Clinic	Other
Medicines my child is taking	X		
Breathing treatments		X	
Coping with my child's illness		X	
Home medical equipment/supplies			Call your home care company. Please call us if you are having trouble despite talking to your home care company.
Whether my child is gaining enough weight		X	
Concerns about oral/tube feedings		X	
Concerns about developmental delays		X	
Weaning my child's oxygen		X	

Helpful contact information:

Pediatrician: _____

Pharmacy: _____

Home care vendor oxygen: _____

Home care vendor feedings: _____

Specialist: _____

Specialist: _____

Specialist: _____

Specialist: _____

Specialist: _____

Summary

We are so excited to partner with you on the next steps of your BPD journey. It is important to realize that the rollercoaster you have been on doesn't end with discharge from the hospital. There will be ups and downs over the next few years, but we are here to help you and your family.

Children grow at the fastest rate in the first two years of life. You will be amazed at the changes that happen. Early intervention and proper nutrition are key to helping your child achieve everything they are capable of. Please don't hesitate to ask questions if you have concerns.

Caring for a child with BPD can be hard and scary at times. Surrounding yourself with a good support system is invaluable. We are happy to be a part of your support system. Congratulations on leaving the NICU.



Congratulations



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