# BIRTH DEFECT RESEARCH FOR CHILDREN



What is Premature Birth?

Premature birth occurs when a pregnancy lasts fewer than 37 weeks from conception. Full-term infants are born 38-42 weeks after they are conceived, with the average being 40 weeks. Characteristics of a premature infant include low birth weight, organs not fully developed or not yet functioning correctly, breathing difficulty, and greater risk of problems. Premature babies are often referred to as "preemies."





## How many children have Premature Birth?

Ten percent of all babies in the United States are born prematurely. African American babies are 2-3 times more likely to be born prematurely. Young women or women over the age of 35 are more likely to have premature births.

## **What causes Premature Birth?**

Sometimes premature births have been linked to the mother's lifestyle choices during pregnancy. Premature births may also be due to medical causes or factors outside the mother's control. Causes include but are not limited to:

- Smoking
- Hormone imbalance
- Alcohol and/or drug use
- Poor nutrition
- Age of mother (under 19 or over 35)
- Poor prenatal care
- Maternal infection and illness during pregnancy
- Chronic illness
- Previous preterm delivery
- Fetal anomalies
- History of multiple pregnancy losses
- Multiple fetuses
- Structural abnormality of the woman's reproductive organs

## How can you help a Premature Infant?

Premature babies are kept in the hospital in the neonatal intensive care unit (NICU) where they receive special treatment to help their survival. Because they lack the body fat necessary to maintain their body temperatures, incubators or radiant warmers are used to keep them warm. Their digestive systems are immature and they have special nutritional needs which require that they be fed slowly through a tube that goes from their nose or mouth to their stomach. They are usually fed breast milk with special fortifiers added.

Potential health problems during the infancy period include:

**Anemia**—low number of red blood cells (cells which are necessary to carry adequate oxygen to the body); may require transfusion.

**Apnea**--baby stops breathing; treated with medication or a nasal device which blows air into the baby's airway.

**Bronchopulmonary Dysplasia**--lung reaction to oxygen; treated with medication.

**Hyperbilirubinemia**--high levels of bilirubin which cause jaundice (yellow discoloration of the skin and whites of the eyes); treated by placing infant under lights that help eliminate bilirubin.

**Infection**--treated with medication.

Intraventricular Hemorrhage (IVH)--bleeding into and around the ventricles of the brain; no specific treatment. The most common complication of IVH is hydrocephalus which is excess fluid in the brain. It is treated with medication and a shunt to allow drainage of the fluid.

**Low Blood Pressure**—treated by increasing fluids or giving medication.

**Necrotizing Enterocolitis (NEC)**—inflammation which causes injury to the bowel; treated with medication and surgery, if necessary.

Patent Ductus Arteriosus—the blood vessel, which normally closes shortly after birth, stays open which causes excess blood to flow into the lungs; treated with medication and surgery, if necessary.

Periventricular Leukomalacia (PVL)--softening of the brain near the ventricles due to death of brain tissue; no specific treatment.

Respiratory Distress
Syndrome-lungs do not



produce enough surfactant which is a substance which helps the lungs expand properly; treated with a ventilator and the use of artificial surfactant.

**Retinopathy of Prematurity (ROP)**—abnormal growth of the blood vessels in the eye; some cases resolve spontaneously, others require laser treatment.

What's in the future for a Premature Baby?

Premature babies have a higher risk of some health and developmental problems. The following checklists and information will help you monitor your preemie's development. A baby born prematurely will continue to develop at the same pace as if he/she were still in the womb. Therefore, experts advise using the child's "corrected age" when evaluating his/her development until he/she reaches the age of two. The "corrected age" is the actual age from birth minus the amount of time the child was premature.

### Hearing

The following is a checklist for evaluating your child's hearing:

#### Due date:

Responds to loud sound Appears to listen to speech

## 3 months:

Smiles when spoken to Turns toward person speaking Recognizes mother's voice

#### 6 months:

Notices new sounds and looks for their source Enjoys vocal play

Coos in more than one tone

### 9 months:

Turns or looks when called Listens to sounds or people talking

### 12 months:

Babbles

Has a vocabulary of 3 words

### 18 months:

Has a vocabulary of at least 8 words Responds to rhythm music Has a way of indicating "no" Understands and responds to requests After 24 months hearing loss may be suspected if:

- Child doesn't pay attention when someone is speaking
- Child can't follow simple directions
- Child has fewer words than other children his/ her age
- Child's speech is difficult to understand

Babies are usually tested for hearing problems around the time of their discharge from the hospital. If the testing indicates an irregularity, the test will be verified by another test at a later date. Early detection of hearing impairment is important for prompt treatment and for proper speech and language development. If you have reason to suspect your child has a hearing problem, you should contact your child's doctor. Specialists will determine the location of a hearing problem before deciding on the best treatment. Mild hearing losses can be treated with the use of hearing aids. In cases of severe hearing loss, children may need to learn other forms of communication such as sign language or lip reading.

## **Speech/Language Development**

The following is a checklist for evaluating your child's speech/language development:

## Birth to 5 months:

Reacts to sound
Watches your face when you speak
Makes noise when spoken to

Makes cooing sounds

Makes pleasure and displeasure sounds

### 6-11 months:

**Babbles** 

Understands "no"

Tries to repeat your sounds

### 12-17 months:

Makes nonsense speech with tone and cadence of human speech

Tries to imitate words

Says a few simple words though may be unaware of their meanings



### Follows simple directions

Points to pictures, objects, family members Answers simple questions nonverbally

#### 18-23 months:

Says 8-10 words

Makes simple sentences such as

"more crackers"

Begins to use pronouns such as "mine"

Asks for common foods by name

Pronounces most vowels correctly

Understands simple verbs such as "eat"

Points to body parts

## **2-3 years:**

Knows 40-50 words

Speaks in 2-3 word phrases

Uses plural words and past tense verbs

Uses question inflection to ask for something

Answers simple questions

### 3-4 years:

Uses most speech sounds

Uses verbs ending in "ing"

Identifies colors

Describes the use of objects

Begins expressing ideas and feelings

Speaks so that strangers understand most of

what's said

Has fun with language; enjoys poems

### **4-5 years:**

Says about 200-300 words

Uses some irregular past tense verbs

Understands spatial concepts such as "next to"

**Defines words** 

Describes how to do things

Lists items that belong in categories

Understands complex questions

Answers "why" questions

## 5 years:

Engages in conversation; uses compound and complex sentences

complex sentences

Makes sentences of 8 or more words

Describes objects

Understands more than 2,000 words

Understands rhyming

Uses imagination to create stories

Prematurely born children with the following conditions may be more prone to problems with speech or language development:

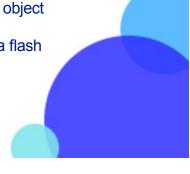
- Weak oral muscles
- Hearing impairment
- Swallowing disorders
- Motor skill problems
- Breathing problems
- Cognitive impairment
- · Birth defects such as cleft lip or palate

A speech disorder refers to a problem with the production of sounds. Speech disorders can include stuttering, saying words incorrectly to the point where others can't understand what's being said, and problems with the volume, pitch, or quality of the voice. A language disorder refers to problems communicating ideas because of difficulty in understanding and putting words together. Language disorders can include limited vocabulary, inability to use language in an appropriate way, and difficulty processing language. If you suspect problems in your child's speech or language development, it is important to intervene quickly. The most intensive period of speech and language development for a child is during the first three years. A speech/language evaluation can help determine the nature of a child's difficulties and help determine the most beneficial course of action. Children involved in speech/language therapy early in their development tend to have more success than children who begin therapy later.

### **Eyes/Vision**

Any of the following situations could indicate a problem with your child's eyes and should be reported to her/his doctor:

- Inability to follow a moving object
- Lazy eye (slow to move)
- Failure to blink at a camera flash in the face
- Abnormal head tilt
- Crying and turning away from normal lighting
- Crossing or wandering





#### eyes

- An eyelid which droops and covers the pupil
- Jerking of the eyes when looking straight
- Cloudy or white appearance on the surface of the eye or pupil
- Constant movement of the eyes especially when trying to focus on an object
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Infants meeting the eye specialists and hospital's Retinopathy of Prematurity (ROP) screening criteria receive eye examinations in the NICU to check for ROP (abnormal growth of blood vessels in the eye). Some specialists suggest that these children should be routinely re-examined at 6 months and 3 years. If there is a history of ROP, former preemies should have yearly retinal exams during adolescence and early adulthood to check for late onset retinal detachment.

Premature children have an increased risk of myopia (near-sightedness), strabismus (wandering or crossed eyes), amblyopia (lazy eye), nystagmus (jerking movements of the eye), decreased color vision, and smaller fields of vision. Myopia can usually be successfully corrected with eyeglasses. Strabismus is usually treated with eye patching or eyeglasses and surgery, when necessary. Amblyopia is also treated with eye patching. Nystagmus cannot be corrected with eyeglasses, but they may help with focusing problems. Additionally, stimulation to encourage use of the eyes and to develop hand-eye coordination is important at an early age. It is important to check frequently during the first few years of life for strabismus and amblyopia. Glaucoma has been found in former preemies during the period of 12-45 years of age so periodic glaucoma testing is recommended.

It is important to treat eye problems early since poor vision can interfere with motor activities such as walking and can slow mental development when a child is unable to recognize objects and learn letters.

## **Nervous System Development**

Serious abnormalities that may occur as a result of neurological injury include:

- Tight or stiff muscles
- Seizures
- · Holding legs straight most of the time
- Deafness
- Moving one side more than the other
- Blindness
- Abnormal crawling; walking on toes
- Slow mental development
- Delay or inability to sit, crawl, stand, or walk

Less serious problems may be more difficult to detect until the child reaches preschool or grade school:

- Short attention span
- Poor coordination
- Difficulty with hand-eye coordination
- Poor balance

Nervous system development includes the achievement of motor skills like smiling, sitting, and walking, as well as the positioning and tone of the muscles. This development can be affected by early neurological injury.

Many children born prematurely will encounter some movement difficulty related to early neurological injury. These impairments are not usually noticeable during the newborn period but may slowly emerge over time. Mild motor abnormalities may improve and completely resolve with time. Movement difficulty affecting the legs is a frequent consequent of brain injury to a premature child. Periventricular Leukomalacia (softening of the brain near the ventricles due to death of brain tissue) and Intraventricular Hemorrhage (bleeding into and around the ventricles) are two common forms of brain injury which can sometimes be identified during the neonatal period. When significant movement impairment persists as a child develops,



diagnosis of cerebral palsy may be considered. In this disorder, the brain has difficulty transmitting the necessary impulses to the muscles to coordinate movement. This diagnosis is not made unless and until it becomes apparent the movement difficulties are not likely to resolve. Cases can range from mild to severe. Most former preemies diagnosed with cerebral palsy will have the spastic diplegia form which involves an involuntary increase of muscle tone. It primarily affects the limbs with legs and feet affected more frequently than arms and hands. Since preemies often have low muscle tone during the neonatal period, the tightness associated with spastic cerebral palsy may not be apparent until after several months at home. Usually only the most severe cases of cerebral palsy are diagnosed during the first several months, and mild cases may not be diagnosed until after the second year when it becomes apparent that problems are not resolving with development. If you have concerns regarding your child's development or observe something that you think is abnormal, talk with your child's doctor.

## **Learning Disabilities**

Knowing some of the signs of learning difficulties may help you identify whether your child has a learning disability:

Difficulty copying words or pictures

Difficulty with abstract thinking

Difficulty learning handwriting

Slow to grasp new concepts

Difficulty with sequencing

Difficulty making decisions

Poor memory

Avoiding classroom participation

Difficulty remembering words

Difficulty with spatial relationships

Difficulty understanding the meaning of sentences

Difficulty following directions, especially if there is more than one step

Problems telling the difference between letters, numbers, or sounds

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A learning disability is a disorder in one or more of the central nervous system processes that can manifest as difficulty in speaking, reading, writing, spelling, listening, reasoning, and/or doing mathematical calculations. Learning disabilities are more common in former preemies. They often become apparent as a child approaches school age. Early diagnosis is important for evaluation and intervention. If you suspect your child has learning difficulties, talk with your child's doctor or teacher. An educational assessment of your child's learning problems can be arranged through your school system or a licensed psychologist.

### **Behavioral Development**

The following may indicate behavior problems in preschool-age children:

- Refusal to comply with requests
- Excessive fear
- Severe or age-inappropriate temper tantrums
- Inability to play quietly
- Inability to stay seated for short activities
- Constant movement
- Aggressive play which causes other children to avoid playing with them

Possible indications of behavior problems for school-age children include:

- Not paying attention
- Fighting
- Doing poorly in school
- Stealing
- Not following directions
- Extreme shyness
- Not wanting to play with





others • Impulsive behavior

• Difficulty sitting still for short periods of time Behavior is a complex interaction of many factors of your child's make-up and environment. Behavior problems are more common for former preemies, and children with learning problems are at a greater risk for behavioral problems. Behavioral problems can mask learning problems so it is important to rule out learning problems as the cause of behavior problems. Children with behavior problems can benefit from consistency in rules, defined limits, and structured environments. Your child's teacher or doctor may be able to assist you in restructuring your child's environment. It is important to address behavioral problems because they can interfere with your child's learning.

#### **Dental**

Former preemies have increased risk for the following dental problems:

- delayed teething (can be 2-6 months late)
- abnormal bite (cross-bite)
- high arch or groove on the roof of the mouth
- abnormal formation of enamel

Indications of abnormal enamel formation include uneven surfaces, abnormal shape, and yellow or brown coloring on the teeth. Poorly formed enamel leads to increased risk of tooth decay. Good oral hygiene and not allowing a child to sleep or nap with a bottle can help prevent tooth decay. The shape of your child's palate may affect his/her speech and bite and may determine whether he/she will need braces. It is recommended that your child see a dentist by his/her first birthday and have regular appointments thereafter as recommended by the dentist. Your child may benefit by seeing a dentist who has experience treating premature children.

Fact Sheet by:

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