

## **HCPCFC PROGRAM**

#### <u>HEALTH CARE PROGRAM FOR CHILDREN</u> IN <u>FOSTER CARE</u>.

#### **COURT FLASH NEWSLETTER**

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#### **Medical Information Fact Sheet**

# **Down Syndrome**

## What is Down Syndrome?

Down syndrome is set of mental and physical symptoms that result from having an extra copy of Chromosome 21 (also called trisomy 21 because there are three copies of this chromosome instead of two), which changes the body's and brain's normal development. It affects 1 in 800 to 1 in 1000 live born infants.

## What are the signs and symptoms of Down syndrome?

Even though people with Down syndrome may have some physical and mental features in common, symptoms of Down syndrome can range from mild to severe. Usually, mental development and physical development are slower in people with Down syndrome than in those without the condition. Most people with Down syndrome have IQs that fall in the mild to moderate range of Intellectual and Developmental Disabilities (IDDs). They may have delayed language development and slow motor development.

Some common physical signs of Down syndrome include:

- Flat face with an upward slant to the eye, short neck, and abnormally shaped ears
- · Deep crease in the palm of the hand
- White spots on the iris of the eye
- Poor muscle tone, loose ligaments
- Small hands and feet

There are a variety of other health conditions that are often seen in people who have Down syndrome, including:

- Congenital heart disease
- Hearing problems
- Intestinal problems, such as blocked small bowel or esophagus
- Celiac disease
- Eye problems, such as cataracts
- Thyroid dysfunctions
- Skeletal problems
- Dementia—similar to Alzheimer's

#### What is the treatment for Down syndrome?

Down syndrome is not a condition that can be cured. However, early intervention can help many people with Down syndrome live productive lives well into adulthood.

Children with Down syndrome can often benefit from speech therapy, occupational therapy, and physical therapy for gross and fine motor skills. They might also be helped by special education and special attention at school. Many children can integrate well into regular classes at school.

About 40 - 60 percent of babies born with Down syndrome have a heart defect. Therefore, all newborns with Down syndrome would have their heart checked with an electrocardiogram and an echocardiogram.

Some infants with Down syndrome have difficulties with swallowing or they may have blockages in their bowels. Surgery can be performed to correct these problems.

Children with Down syndrome may have frequent colds and sinus and ear infections. These are treated early and aggressively to prevent hearing loss and chronic infections.

Low thyroid levels are more common in infants who have Down syndrome. It is therefore recommended that thyroid level testing be performed at least yearly.

Some infants with Down syndrome have eye problems such as cataracts (cloudy lenses) or crossed eyes (strabismus). Surgery can help with these problems.

Sucking problems related to low muscle tone or heart problems may make breast feeding difficult initially. Occupational therapists, speech therapists, breast feeding consultants and support groups usually have specific resources for the mothers of infants with Down syndrome.

Intelligence in individuals with Down syndrome ranges from low normal to very slow to learn. At birth it is not possible to tell the level of intelligence a baby with Down syndrome will have.

All areas of development including motor skills, language, intellectual abilities, and social and adaptive skills are followed closely in children with Down syndrome.

Early referral, beginning at birth, to an early intervention program will help enhance development. Preschool programs for children with Down syndrome include physical, occupational, speech and educational therapies.

Many adults with Down syndrome have jobs and live independently.

## Who is at risk for Down syndrome?

The chance of having a baby with Down syndrome increases as a woman gets older—from about 1 in 1,250 for a woman who gets pregnant at age 25, to about 1 in 100 for a woman who gets pregnant at age 40. But, most babies with Down syndrome are born to women under age 35 because more younger women have babies.

Because the chances of having a baby with Down syndrome increase with the age of the mother, many health care providers recommend that women over age 35 have prenatal testing for the condition. Testing the baby before it is born to see if he or she is likely to have Down syndrome allows parents and families to prepare for the baby's special needs.

Parents who have already had a baby with Down syndrome or who have abnormalities in their own chromosome 21 are also at higher risk for having a baby with Down syndrome.

Once the baby is born, a blood test can confirm whether the baby has Down syndrome.

Down Syndrome. (2011, February). National Institute of Child Health & Human Development: National Institutes of Health. Retrieved June 20, 2011 <a href="http://www.nichd.nih.gov/health/topics/down\_syndrome.cfm">http://www.nichd.nih.gov/health/topics/down\_syndrome.cfm</a>

Down Syndrome. (2010, December). Genome.gov National Human Genome Research Institute: National Institutes of Health. Retrieved June 20, 2011 http://www.genome.gov/19517824

## **Cleft Lip and Palate**

#### **Definition:**

Cleft lip and palate are birth defects that affect the upper lip and the roof of the mouth. A cleft is a gap in a body structure that results from incomplete closing of a specific structure during development. Some babies have only a cleft lip. However, many babies with cleft lip have a cleft palate as well.

#### Causes:

There are many causes for cleft lip and palate. Genetics, drugs, viruses, or other toxins can all cause such birth defects. Cleft lip and palate may occur along with other syndromes or birth defects such as Waardenburg, Pierre Robin, and Down syndromes. About 1 out of 2,500 people have a cleft palate.

## Symptoms:

A child may have one or more of these conditions at birth. A cleft lip may be just a small notch in the lip. It may also be a complete split in the lip that goes all the way to the base of the nose. A cleft palate can be on one or both sides of the roof of the mouth. It may go the full length of the palate.

Problems that may be present because of a cleft lip or palate are:

Failure to gain weight/ poor growth due to feeding problems

Flow of milk through nasal passages during feeding

Misaligned teeth

Recurrent ear infections

Speech difficulties

Change in nose shape (amount of distortion varies)

## Signs and Testing:

A physical examination of the mouth, nose, and palate confirms a cleft lip or cleft palate. Medical tests may be done to rule out other possible health conditions. A child with cleft lip or palate is often referred to a multidisciplinary team of experts for treatment. The team may include: an otolaryngologist (ear, nose, and throat specialist), plastic surgeon, oral surgeon, speech pathologist, pediatric dentist, orthodontist, audiologist, geneticist, pediatrician, nutritionist, psychologist and social worker.

## Treatment/Expectations:

Surgery to close the cleft lip is often done when the child is between 6 weeks and 12 months old. Surgery may be needed later in life if the problem severely affects the nose area. The surgical procedure is called palatoplasty.

A cleft palate is usually closed within the first year of life so that the child's speech normally develops. Sometimes a prosthetic device is temporarily used to close the palate so the baby can feed and grow until surgery can be done.

Cleft Lip and Palate. (2009, May). Cleft Lip and Palate. Retrieved June 20, 2011 http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002046/

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#### HCPCFC PROGRAM UPDATES AND ANNOUNCEMENTS.

HCPCFC nurses continue to collaborate and coordinate with various departments and agencies to ensure the health and safety of children in foster care.

