

# Health Care Information for Families of Children and Adolescents with Down Syndrome

## Child's Age: 1 Month to 1 Year

### **Regular well-care visits (check-ups)**

While infants with Down syndrome might need multiple special visits to their doctor and specialty physicians, it is very important that they get regular well-care visits (check-ups). These visits will include checking your child's health, giving immunizations (shots), and building the relationships between the doctor and the family. Developing these relationships will help support the medical and other needs of the child and the family.

### **Monitor growth**

It is important to check growth at every visit. Measurements include height, weight, weight for height, and head circumference. Your child's growth can be shown on the Down Syndrome Growth Charts. Discuss your child's diet, activity level, bowel and urine patterns, and growth. Your child's doctor can help with questions about any need for vitamins or supplements.

### **Immunizations (shots)**

Your child's doctor should follow the same shot schedule as for any other child. This includes yearly influenza (flu) shots. It may include other shots, too, depending on your child's health history.

### **Heart**

If there were any signs of heart disease in the first month of life, heart monitoring is probably already in place. Heart problems could still worsen, or new ones could arise. If concerns exist, it is very important to act early. Breathing that is too fast or cyanosis (a bluish color of the skin) are signs for possible concern.

### **Hearing and vision**

Infants with Down syndrome are at risk for eye problems leading to vision loss or ear problems leading to hearing loss. It is important to have both vision and hearing checked by specialists (ophthalmologist and otolaryngologist/ear, nose, and throat doctor or ENT). The eyes should be tested at birth and again at 1 year or sooner if there are concerns. Hearing should be tested at birth and again every 6 months in early childhood to be sure that the baby's hearing is the best possible.

### **Thyroid**

Thyroid hormone levels can be too low in infants and need to be checked (a TSH test). Low thyroid levels can cause a variety of problems that might not be easy to detect without a blood test. A TSH should be obtained at birth and again at age 6 months and 1 year.

### **Blood tests**

Tests for low iron (ferritin, serum iron, and other tests) and anemia (CBC and other tests if needed) should be done every year. Low ferritin can be associated with sleep problems, and your doctor may prescribe iron.

### **Stomach or bowel problems (reflux, constipation, blockages)**

Intestinal issues can occur. Spitting up, stomach swelling, or an abnormal stool pattern can be signs that there is an issue.

### **Neurology**

Children with Down syndrome have an increased risk for seizures including infantile spasms. Your child's doctor will ask about these symptoms.

### **Neck instability**

Bones in the neck or spine can be unstable in some people with Down syndrome. There are almost always visible signs when there are problems. Daily physical activity is important to your child and should not be limited by unneeded worries. X-rays are not needed unless there is pain or changes in the use of hands, walking, or bowel or bladder function. If x-rays are done and the results are abnormal, your child may be referred to a spine or neck specialist. It is recommended that the neck be positioned properly for any medical procedures.

### **Developmental services**

Developmental services (for example, early intervention programs) can be of great benefit to the family with a child with Down syndrome. Developmental services can also help arrange for other related services. These services should provide information to your child's doctor to maintain a close working relationship with the doctor and the family.

**Social support services**

Many families need additional help with the issues that can arise with the care of children with Down syndrome. All families should discuss with their doctor the social services that may be available and their benefits.

**Counseling for chance of recurrence**

Families should get counseling about the possible chance of having another child with Down syndrome, if they choose to have more children. While the chance is usually low, other factors in the family history might be present, so counseling should be done after a complete review of the family history.