Down Syndrome in Florida

Down syndrome is…

a genetic condition that occurs in about 1 of every 769 babies born in Florida and in about 1 of every 700 babies born in the United States. Babies with Down syndrome are born with three, instead of two, copies of chromosome number 21. The extra chromosome 21 tends to affect each person with Down syndrome in different ways. Throughout their lives, individuals with Down syndrome may need tailored support to meet their unique developmental, educational, medical, and social needs.

Children with Down syndrome are at higher risk for…

- Hearing loss (75%)
- Obstructive sleep apnea (50–75%)
- Ear infections (50–70%)
- Eye diseases (60%) like cataracts (15%) and issues requiring glasses (50%)
- Heart defects present at birth (50%)
- Intestinal blockage requiring surgery (12%)
- Hip dislocation (6%)
- Thyroid disease (4–18%)
- Anemia (3%) and Iron deficiency (10%)
- Leukemia (1%) and Hirschsprung disease (<1%) later in life

Individuals with Down syndrome usually have some of these conditions during their lifetime. The majority of these conditions, including conditions of the heart and digestive problems, can be surgically treated during the first years of life.

Support with caring for your child…

Families can benefit from programs that help identify infants and children at risk for developmental delays. For children, birth to 36 months of age, Early Steps, Florida’s early intervention program helps families and others involved in the child’s life develop the needed skills to nurture their child’s growth and development.

Visit www.cms-kids.com/families/early_steps/early_steps for more information.

Most families of children with Down syndrome find connecting with other families of children with Down syndrome helpful. Please see the list of parent support groups on the reverse side.
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Children, adolescents and adults with Down syndrome will need specialized assistance when…

- Entering school for the first time or moving to middle and high school
- Transitioning to adulthood and
  - Finding an adult doctor
  - Identifying a guardian
  - Renting an apartment
- Deciding/trying to live alone
- Being in adult relationships
- Starting families of their own
- Outliving their caregivers

Many students with Down syndrome graduate from high school, and go on to receive higher education including attending college and working in jobs where they are valued.

Additional state resources for families affected by Down syndrome:

- Florida Birth Defects Registry (FBDR): www.fbdr.org, (850) 245-4444
- Children’s Medical Services (CMS): www.cms-kids.com
- Florida Directory of Early Childhood Services: www.centraldirectory.org

For parent support groups and advocacy organizations in your area, visit:

- Central Florida Parent Center: www.cflparents.org
- Down Syndrome Association of Central Florida: www.dsacf.org
- Down Syndrome Foundation of Florida: www.dsfflorida.org
- Hope Haven: www.hope-haven.org
- National Down Syndrome Society (lists support groups throughout Florida): www.ndss.org
- The Arc-Florida: www.arcflorida.org

For more information visit:

- American College of Medical Genetics: www.acmg.net/GIS/Default.aspx
- American Academy of Pediatrics: www.aap.org
- Down Syndrome Research and Treatment Foundation: www.dsrtf.org

Florida’s Early Steps Program: www.cms-kids.com/families/early_steps
- March of Dimes: www.marchofdimes.com
- National Birth Defects Prevention Network: www.nbdpn.org
- National Center For Prenatal and Postnatal Down Syndrome Resources: downsyrndromediagnosis.org
- National Center on Birth Defects and Developmental Disabilities: www.cdc.gov/ncbddd
- National Down Syndrome Congress: www.ndsccenter.org
- National Dissemination Center for Children with Disabilities: www.nichcy.org
- National Society of Genetic Counselors: www.nsgc.org

Down syndrome can be detected prenatally and postnatally. If a family receives a diagnosis of Down syndrome it is important that an echocardiogram be performed to detect if a heart defect is present. 50% of children with Down syndrome have a heart defect and about 1/3 may require surgery. Families with a history of Down syndrome or other birth defects should seek guidance from a genetic counselor before planning a pregnancy to assess their risk of recurrence.

Research is currently being conducted to improve outcomes for people with Down syndrome. Infants, children and adults with Down syndrome will benefit from programs that help to improve their physical and mental functioning disabilities. These include speech, physical and occupational therapy, exercise for physical coordination, receiving extra help or attention in school and having a work coach to help them on the job.