Youth and Down’s Syndrome

What is Down’s Syndrome?
Down’s syndrome is a genetic birth defect that causes delays in physical and mental development. People with Down’s syndrome have 47 chromosomes instead of the typical 46 that most people have. There are two copies of chromosome 21.

What Causes Down’s Syndrome?
Down’s syndrome is caused by an error in cell division that occurs at conception. There is increased risk of giving birth to a child with Down’s syndrome as the age of a mother increases. However, many children with Down’s syndrome are born to younger mothers.

What are the Characteristics of Down’s Syndrome?
Most children with Down’s syndrome are developmentally delayed. They complete most developmental tasks but do so at a later age than do children without Down’s syndrome. For instance, most children learn to walk between 10 and 14 months of age. Children with Down’s syndrome typically learn to walk between 18 and 24 months of age. Other characteristics include:

- Upward slanting eyes,
- Flat face,
- Small ears,
- Large tongue,
- Short neck,
- Small hands with short fingers,
- Crease inside of palm,
- Small head size,
- Wide gap between first and second toes,
- Speech and language delays,
- Mild to moderate retardation (a few individuals may not be classified as mentally retarded and may have IQ’s in the average range),
- Average life span of 55 years.
What Medical Problems are Associated with Down’s Syndrome?

There are several medical problems typical in individuals with Down’s syndrome. These include:

- Obesity,
- Hearing loss,
- Skin problems,
- Congenital heart disease,
- Muscle weakness,
- Higher incidence of infection,
- Dental problems,
- Higher incidence or leukemia,
- Alzheimer-type dementia after 35 years of age.

What is the Treatment for Down’s Syndrome?

There is no cure for Down’s syndrome. Treatment includes prevention of medical issues such as skin or dental problems through proper hygiene, possible surgery for congenital heart disease, and special education courses that facilitate the best learning environment possible to allow a child with Down’s syndrome to develop to the best of his or her ability.

Important Issues for Extension Educators and 4-H Leaders to Consider:

1. Have contact information for parents or guardians and the member’s doctor in accessible places. An example of this would be behind the child’s nametag and in the medical forms box in the main office at 4-H events. This form should include information such as what kinds of medications the child is taking, allergies, if any adaptive devices are used, and other health conditions.

2. Visit with the member and his or her family about their particular case of Down’s syndrome. Questions that can be asked include: “What projects are you interested in, and how can we best modify them for you?” and “What health problems do you have that I should be aware of?”

3. One popular myth is that people with Down’s syndrome are always happy. This is simply not the case. 4-H members with Down’s syndrome have emotions and feelings, both positive and negative, like all other 4-H members.

4. A member with Down’s syndrome may get lost in a long list of instructions. Break tasks and activities down into small pieces to avoid frustration and to make the best learning situation for the member.

5. Members with Down’s syndrome may be easily influenced by other 4-H members or by people not associated with the organization. While friendships should be fostered between a member with Down’s syndrome and others, keep close watch that the member with Down’s syndrome is not being taken advantage of.

For More Information Contact:
National Down’s Syndrome Society
666 Broadway
New York, NY 10012
Phone: (800) 221-4602
Web site: www.ndss.org
(Web site active as of May 6, 2005)

Acknowledgements:
Appreciation is extended to the following reviewers: Matthew Cavedon, trustee, National 4-H Council; Terri Dawson, director, Parent Information Center, Buffalo, Wyoming; Roger Tormochlen, head, Department of Youth Development and Agricultural Education, Purdue University; and Karen C. Williams, associate professor and head, Department of Family and Consumer Sciences, University of Wyoming.

Special thanks is also given to David K. Carson, former professor of Family and Consumer Sciences at the University of Wyoming and Kent Becker, associate professor of Counselor Education at the University of Wyoming for comments on earlier versions of the articles in this series.

Inclusive 4-H coordinator, Randolph Weigel, professor and human development specialist, University of Wyoming Cooperative Extension Service.