



**ABOUT A GIRL** Sophia Whitten, five, mugs for the camera.

# Bright Future

A new medical institute holds hope for those with Down syndrome.

**Like most five-year-olds**, Sophia Whitten dances and plays pretend, loves her brother's toys, and has a heartwarming smile. Unlike most children, she was born with an extra copy of chromosome 21, which alters the development of the brain and body. In Sophia's case, the extra gene necessitated open-heart surgery when she was three months old to fix a missing septum and valve defects.

Sophia is one in about 100 Colorado children born with Down syndrome every year. Unfortunately, Colorado ranks 46th out of 50 states in funding for people with developmental disabilities. The situation didn't improve with the failure to pass Amendment 51 on last year's November ballot; it called for a small increase in the state sales tax to provide care for developmentally disabled Coloradans. And while Down syndrome is the most common chromosomal abnormality, it receives the least amount of research funding from the National Institutes of Health. Plus, private money for Down syndrome largely goes to prenatal testing as opposed to quality-of-life programs such as health care or social mentoring. "It's terrible for our kids if you look at the services," says Michelle Whitten, Sophia's mother.

With 6,000 Coloradans living with Down syn-

drome, why the lack of support? As recently as the 1980s, the life expectancy for someone with Down syndrome was in the mid-20s. Until the 1970s, anyone affected by the condition was institutionalized. Today, however, the average life expectancy is 55 to 60. The challenge is to secure the resources and funding to provide a quality life. "The focus should be

on the abilities, not on the disabilities," says Sarah Hartway, director of professional partnerships with the Mile High Down Syndrome Association.

As of this year, children with Down syndrome like Sophia have reason to hope. A \$34 million endowment from the Anna and John J. Sie Foundation (the Sies are Sophia's grandparents)

in September established a new global medical research center, the Linda Crnic Institute for Down Syndrome, on the Anschutz Medical Campus. The facility aims to eliminate the health and cognitive side effects of Down syndrome, such as heart defects and mental retardation, through clinical trials, medical care, and advocacy. "It's not an impossible dream," says Dr. William Mobley, executive director designee of the institute. "It's a unique place where all of these elements will be put together in a way to make this possible."

—JULIE DUGDALE

## HOW TO GET INVOLVED

### Volunteer

Call 303-797-1699 or visit [www.mhdsa.org](http://www.mhdsa.org) for opportunities with the **Mile High Down Syndrome Association**, such as helping to coordinate the annual Buddy Walk awareness event or organizing activities and outings for the "Get Down" social group. Or call 303-563-8290 ext. 16 or visit [www.adamscamp.org](http://www.adamscamp.org) for hands-on opportunities with **Adam's Camp**, a Colorado nonprofit that provides intensive and individualized therapy programs for youth with developmental disabilities.

### Donate

The **Rocky Mountain Down Syndrome Educational Fund** seeks help with funding programs such as performing and visual arts classes for adults with Down syndrome, pilot studies on cognitive ability, and educational symposiums to benefit professionals and community members, from doctors to teachers and parents. Call 303-468-6663 for information on how to contribute.

### Teach

Become a peer mentor for someone with Down syndrome through the "friendS" program at the regional **Denver Adult Down Syndrome Clinic** ([www.denverdsclinic.org](http://www.denverdsclinic.org)). The program is an extension of the clinic's year-round ALIVE! classes on the University of Denver campus, which teach life skills to adults with Down syndrome. Call 303-360-3877 or e-mail [director@denverdsclinic.org](mailto:director@denverdsclinic.org).