



FOR IMMEDIATE RELEASE

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Designer Genes Buddy Walk Celebrates Down Syndrome Awareness

Come join in supporting Down syndrome awareness by taking part in Bismarck's 8th-annual Designer Genes Buddy Walk on Saturday, September 17th at the State Capitol in Bismarck. Registration and entertainment will begin at 10:00 a.m., with the approximately 1-mile non-competitive walk kicking off at 11 a.m. Pre-registration is not necessary and no registration fees are collected from walkers. The walk promotes Down syndrome awareness and is supported by well-appreciated community sponsors. Walkers who wish to donate \$10 or more will receive a walk t-shirt.

WHAT: The Buddy Walk was developed by the National Down Syndrome Society (NDSS) in 1995 to promote acceptance and inclusion of all people with Down syndrome. This year the 2011 Designer Genes Buddy Walk is one of at least 300 Buddy Walk events scheduled from mid-September through November, with more than 285,000 people expected to participate.

WHEN: Saturday, September 17th. Registration and entertainment begins at 10:00 am, with the walk beginning at 11 am.

WHERE: State Capitol Grounds, Bismarck – Registration will be set up at the Capitol Steps and the walk will be conducted around the Capitol loop. (600 E Boulevard Avenue)

WHO: About 1,500 people are expected to attend. Participants include people with Down syndrome from around the state, their families, friends, teachers, coworkers and other supporters. The general public is encouraged to attend and show their support for people of all abilities.

BACKGROUND: Designer Genes does not focus on fundraising during the Buddy Walk, however, last year alone, Buddy Walks across the country raised more than \$11.2 million to benefit national education, research and advocacy initiatives, as well as local programs and services. All funds raised through the Designer Genes Buddy Walk support both local and national programs.

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Designer Genes is a local support network for families of individuals with Down syndrome. Designer Genes is committed to supporting and enhancing the quality of life, and realizing the potential of all people with Down syndrome. We demonstrate this commitment through education and events that benefit people with Down syndrome and their families. Learn more at DesignerGenesND.com



Buddy Walk Talking Points

- The 2011 Designer Genes Buddy Walk will take place on September 17th at State Capitol with Registration and entertainment beginning at 10:00 a.m. and the walk beginning at 11 a.m.
- This is the 8th annual Buddy Walk to take place in Bismarck. It is Designer Gene's goal to use this event to raise awareness about Down syndrome in our community.
- The Designer Genes Buddy Walk is not focused on fund raising, but awareness. We work hard to create relationships with sponsors to raise funds to benefit education, research and advocacy initiatives, as well as local programs and services.
- Roxane Romanick and Sandy McMerty are the Designer Genes Buddy Walk coordinators.
 - Roxane Romanick is the proud mother of 12-year old Elizabeth, a bouncy, bright-eyed little girl with Down syndrome. Roxane is an experienced social worker and currently serves in a number of roles in early education in the community and at the national level.
 - Sandy McMerty is the proud mother of 10-year old Cristian, a sports loving, energetic boy with Down syndrome.
- The Designer Genes was originally founded by local families who had young children with Down syndrome about 20 years ago. This network continues to support parents of children and adults with Down syndrome in many ways.
- Key programs and services of Designer Genes include:
 - Informational packets provided to both local hospitals for families of new babies with Down syndrome.
 - Partnership with Missouri Valley Quilting Guild and local quilters to provide new crib quilts for new babies with Down syndrome.
 - First time visits for families of new babies with Down syndrome.
 - A reading library of pertinent Down syndrome materials.
 - An annual picnic and Buddy Walk.
 - Informational meetings and educational events.
 - One-to-one networking and advocacy.

**Learn more at DesignerGenesND.com or call:
Roxane Romanick – (701) 391-7421 (cell)
Sandy McMerty – (701)425-6518 (cell)**

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Buddy Walk Fact Sheet/Backgrounder

- The Buddy Walk is an national advocacy and awareness program developed by the National Down Syndrome Society in 1995 to celebrate October as National Down Syndrome Awareness Month
- The Buddy Walk has three primary goals:
 - To promote acceptance and inclusion of people with Down syndrome
 - To raise funds for local and national programs
 - To enhance the position of the Down syndrome community, enabling us to positively influence local and national policy and practice
- In the past 15 years, the Buddy Walk has grown from 17 walks to more than 300 across the country and around the world. More than 285,000 people are expected to participate in the Buddy Walk this year
- Last year alone, the Buddy Walk raised more than \$11.2 million nationally to benefit local and national programs and services.
- John C. McGinley, who plays Dr. Perry Cox on the show “Scrubs,” is the 2011 National Buddy Walk Spokesman. Mr. McGinley is both an accomplished actor and the proud father of Max, his son who has Down syndrome
- There are approximately 400,000 people with Down syndrome in the United States.
- Down syndrome affects people of all races and economic levels. It is the most commonly occurring genetic disorder. One in every 733 babies is born with Down syndrome
- Quality educational programs, a stimulating home environment, good medical care and positive support from family, friends and the community at large enable people with Down syndrome to enhance their quality of life and realize their life aspirations.
- Since its inception in 1979, NDSS has served as the national advocate for the value, acceptance and inclusion of people with Down syndrome.

**For more information on the Designer Genes Buddy Walk visit
DesignerGenes.com or call (701) 425-6518.**

**For more information about Down syndrome or the
National Down Syndrome Society, visit NDSS.org.**

Down Syndrome Fact Sheet

- Down syndrome occurs when an individual has three, rather than two, copies of the 21st chromosome. This additional genetic material alters the course of development and causes the characteristics associated with Down syndrome.
- Down syndrome is the most commonly occurring chromosomal abnormality. One in 733 babies is born with Down syndrome. Approximately 5,000 children with Down syndrome are born each year.
- There are more than 400,000 people living with Down syndrome in the United States.
- Down syndrome affects people of all ages, races and economic levels.
- The incidence of births of children with Down syndrome increases with the age of the mother. But due to higher fertility rates in younger women, 80 percent of children with Down syndrome are born to women under 35 years of age.
- People with Down syndrome have an increased risk for certain medical conditions such as congenital heart defects, respiratory and hearing problems, Alzheimer's disease, childhood leukemia, and thyroid conditions. Many of these conditions are now treatable, so most people with Down syndrome lead healthy lives.
- A few of the common physical traits of Down syndrome are low muscle tone, small stature, an upward slant to the eyes, and a single deep crease across the center of the palm. Every person with Down syndrome is a unique individual and may possess these characteristics to different degrees or not at all.
- Life expectancy for people with Down syndrome has increased dramatically in recent decades – from 25 in 1983 to 56 today.
- All people with Down syndrome experience cognitive delays, but the effect is usually mild to moderate and is not indicative of the many strengths and talents that each individual possesses.
- Quality educational programs, a stimulating home environment, good health care, and positive support from family, friends and the community enable people with Down syndrome to develop their full potential and lead fulfilling lives.
- People with Down syndrome attend school, find work, participate in decisions that affect them, and contribute to society.
- Researchers are making great strides in identifying the genes on Chromosome 21 that cause the characteristics of Down syndrome. Many feel strongly that it will be possible to improve, correct or prevent many of the problems associated with Down syndrome in the future.



Date

Reporters name, title

Publication

Address

On September 17, 2011, families from across the state will gather at the State Capitol to participate in the Designer Genes Buddy Walk, an event that promotes acceptance and inclusion of all people with Down syndrome. Not only is this a heartwarming community event, but there are also many fascinating individuals participating in the walk and a number of important issues facing the Down syndrome community today. I am writing to share a couple of these people and issues with you for your consideration as possible feature stories connected to the Buddy Walk and Down Syndrome Awareness Month in October.

2011 Buddy Walk Spokesperson – Gracie Larson: Gracie and her family will lead off the Buddy Walk this year. Gracie, age 6, has an amazing story to tell about her recovery from a significant health issue. In November, 2009, she was hospitalized with a condition called “atlantoaxial instability”. This condition that occurs in a small percentage of persons with Down syndrome causes instability in the cervical spine. Gracie underwent extensive surgeries to overcome this diagnosis. We will celebrate her recovery and the excitement that her family feels as they look forward to her starting public school and being healthy.

2011 Designer Genes Self-Advocate Board Member – Jason Yeager: Jason has served on the Designer Genes Board of Directors for the last three years. Jason’s message is that the chromosomal disorder should be renamed to “Up Syndrome” because being around people with Trisomy 21 usually makes your day rather than bringing your down. Having the diagnosis himself, he successfully lives independently and is currently working at Easter Seals Goodwill. Jason also serves on the Board of Directors for the Arc of Bismarck.

National Executive Director of the Down Syndrome Affiliates in Action trade association – Deanna Tharpe: Designer Genes is proud to say that they are the home to the national direction of Down Syndrome Affiliates in Action (DSAIA). DSAIA brings Down syndrome organizations across the country together to share resources, engage in cooperative purchasing, and to address issues. Deanna and her husband, Jason, who works for Delta Waterfowl moved to the Bismarck-Mandan area in 2010.

Inclusive Practices: It is the hope of Designer Genes that with increased awareness in our communities that more individuals with Down syndrome and disabilities will be given opportunities to demonstrate their potential for meaningful involvement and participation. Hopefully we will see this in our schools, churches, park and recreation activities, neighborhoods, and our workplace. The Buddy Walk serves as a visual demonstration of the people that believe that true inclusion can happen.

Down Syndrome Research: The Down syndrome community is watching closely as new treatments for enhanced cognitive functioning are being developed. Some of these studies are in connection with treatment for Alzheimer’s. In addition, research and development is being conducted in the area of prenatal testing for Down syndrome. The advent of advanced prenatal testing will increase the need for accurate and up-to-date information on Down syndrome for new parents.