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CU Foundation Publications FASHION EVENT TO BENEFIT UC DENVER'S LINDA CRNIC INSTITUTE FOR DOWN SYNDROME

2009 marks the 50th anniversary of identifying the genetic cause of Down syndrome. To commemorate this historic discovery, the Global Down Syndrome Foundation has organized the Be Beautiful Be Yourself Jet Set Fashion Show, a fundraiser featuring honoree Music Icon Quincy Jones, singer-songwriter Josh Kelley and a fashion show including guest models with Down syndrome. The fundraiser, to be held on Saturday, Oct 10, 2009 at the Hyatt Regency Denver at the Colorado Convention Center will benefit the Linda Crnic Institute for Down Syndrome at the University of Colorado Anschutz Medical Campus.

In 1959, the world famous pediatrician, geneticist and scientist, Jérôme Lejeune, discovered the cause of Down syndrome - a third or extra copy of the 21st chromosome. Lejeune spent much of his life specializing in the treatment and care of children with Down syndrome and he felt strongly that a scientific cure for Down syndrome was possible.

"We are pleased to have the opportunity to take up where Dr. Lejeune left off," said M. Roy Wilson, Chancellor of University of Colorado Denver. "Through the leadership of the Linda Crnic Institute for Down Syndrome, his dream of curing the medical and cognitive ill effects associated with the condition will live on."

One of the lead Down syndrome scientists that the Linda Crnic Institute helps to support agrees. Roger Reeves, PhD, Professor at the Department of Physiology at Johns Hopkins University School of Medicine states "We are at a key moment of opportunity in the field of Down syndrome research, looking at the possibility of greatly expanding the ability of people with Down syndrome to realize their full potential. The Linda Crnic Institute and the collaborative opportunities it presents are critically important in this effort. I am confident that life changing discovery for people with Down syndrome is within our grasp scientifically but in order to deliver that promise we need a sea-change in advocacy and funding, and we need to attract more talent to the field. This new institute is so exciting precisely because it is in a prime position to ignite excellent science in Down syndrome in the US and globally."

Down syndrome is the most frequent chromosomal disorder in the United States accounting for 1 in 733 live births. There are over 400,000 people in the US and millions worldwide with the condition. Despite the frequency it is the least funded genetic condition by the National Institutes of Health. In 2008 Down syndrome accounted for just 0.0006 of its \$28 billion budget.

The Be Beautiful Be Yourself Jet Set Fashion Show fundraiser aims to raise over \$1 million - believed to be the largest ever single fundraiser for Down syndrome - and sell out at the Hyatt with 1,200 seats. "What we are doing in United States shows that even outside the families touched by Down syndrome, there is a sincere and unmet desire to help. We are simply showing folks how they can help and at the same time showcasing the fact that our children are brilliant and beautiful," Michelle Sie Whitten, Executive Director of the Global Down Syndrome Foundation said.

The Linda Crnic Institute for Down Syndrome aims to eradicate the ill effects associated with Down syndrome and significantly improve the lives of people with Down syndrome throughout the world. The Institute is named in memory of Dr. Linda Crnic, in honor of her unwavering dedication to people with Down syndrome through translational research. Crnic, who died tragically in a bicycle accident in 2004, was a Professor of Pediatrics and Psychiatry at the University of Colorado School of Medicine and Director of the Colorado Mental Retardation and Developmental Disabilities Center.

The inspiration for the establishment of the Linda Crnic Institute is Sophia Kay Whitten, the granddaughter of Anna and John J. Sie, who happens to have Down syndrome. Through the largest private contribution dedicated to people with Down syndrome in the world, the Anna and John J. Sie Foundation's commitment of \$22 million, and the Sie's commitment to raise another \$12 million ensures the Institute will be a global beacon for research and care.

The Linda Crnic Institute for Down Syndrome is the first national organization to house basic research, clinical research and clinical care for people with Down syndrome under one umbrella. The Institute is a collaboration between the University of Colorado Boulder, the University of Colorado Denver and The Children's Hospital. It is located on the Anschutz

Medical Campus in Aurora, Colorado and is the beneficiary of the proceeds from the October 10 Be Beautiful Be Yourself Jet Set Fashion Show.

Representatives from Down syndrome organizations from the UK, Canada, San Diego, Kansas City, and New York and will be in attendance in addition to the notable Coloradans who are supporting the event including Governor Bill Ritter, Jr. & First Lady Jeannie Ritter, Denver Mayor John W. Hickenlooper & Helen Thorpe, Anna & John J. Sie, Ricki Perry Rest & David Rest, Sharon Magness Blake & Ernie Blake, Mike & Amber Fries, Susanne Arkle Wilson & M. Roy Wilson, Peter & Bonnie Kudla, Laura Barton & William Matthews, Donald & Susan Sturm, Jordon & Essie Përtmutter, Robin Chotin, Steven Chotin, Dr. Dean Prina, Jack & Pat McDonnell, Debbi & Lee Alpert, Cookie & Lester Gold, Susan & Randy Karsh, Shereen & Michael Pollack, and Steve & Cindy Farber.

Tickets are on sale now for the Be Beautiful Be Yourself Jet Set Fashion Show featuring honoree Music Icon Quincy Jones, singer-songwriter Josh Kelley, a Saks Fifth Avenue fashion show, and local celebrities including John Lynch, Ed McCaffrey, 2009 Miss Colorado Katie Layman and Billy Van Heusen on Saturday, Oct. 10, 2009 at the Hyatt Regency Denver at the Colorado Convention Center.

For more information or tickets, call Diana Moore at the Global Down Syndrome Foundation at 303-468-6663 or visit www.coloradojetset.com.

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