The Global Down Syndrome Foundation

The Global Down Syndrome Foundation is a nonprofit corporation dedicated to significantly improving the lives of people with Down syndrome by supporting basic research, clinical research and clinical care.

Established in 2009, the foundation's primary focus is to support the Linda Crnic Institute for Down Syndrome. The institute is the first organization in the U.S. with the mission to eradicate the medical and cognitive ill effects associated with Down syndrome through basic and clinical research and clinical care. The institute incorporates scientific partners both locally and globally, with head-quarters at the Anschutz Medical Campus in Colorado.

The foundation, originating from start-up funds made possible by the Anna and John J. Sie Foundation, will provide desperately needed funds to underwrite research for people with Down syndrome. In doing so, the Global Down Syndrome Foundation is not just addressing the 400,000 people in the United States with Down syndrome but the millions of people affected by the condition worldwide.

The foundation builds community awareness by focusing on the abilities of and contributions made by people with Down syndrome, and creating awareness about the unique and sometimes heart-wrenching, challenges that people with Down syndrome and their family members face.

The foundation intends to continue its successful Be Beautiful Be Yourself Jet Set Fashion Show fundraiser that highlights models with Down syndrome, and to co-host similar fashion show fundraisers in other states and countries.

In addition to fundraising that incorporates awareness, the foundation will partner with the Rocky Mountain Down Syndrome Educational Fund and other organizations to organize and promote advocacy and educational events that will benefit people with Down syndrome.

The foundation has already taken a leadership role in educating members of Congress, the National Institutes of Health and other governmental organizations about the outrageous discrepancy in the research funding benefiting people with Down syndrome. Down syndrome is the least funded genetic condition by the National Institutes of Health, garnering only 0.0006 of the 2008 budget despite being the most frequent chromosomal condition with 1 in 733 children in the U.S. born with Down syndrome. This educational role is pivotal in accessing research funds that are crucial in creating a brighter future for people with Down syndrome.

For more information on how to join the Global Down Syndrome Foundation and its events, contact Executive Director Michelle Sie Whitten at 303-468-6663.

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office one day with his stepbrother, he saw a Spinet piano in the corner. When he almost closed the door, Jones heard God say, 'Idiot, go back into that room.'

"I walked back into that room and went to the piano. I never thought about a human being playing it, had heard it all my life but when I touched it, every cell in my body said, this is what you will be doing for the rest of your life. It saved my life – at 11 years old," Jones said.

That Spinet piano changed his life and consequently, many others lives he touched. In addition to the piano, he mastered other musical instruments including percussion, drums, tuba, sousaphone, French horn and trombone.

Jones said he was fortunate to work with so many great people such as composers Salvador Poe and Leonard Bernstein, French composer and teacher Nadia Boulanger, actress Bridget Bardot and others who helped shape his future. They saw the greatness in him before he saw the greatest in himself.

"And she (Nadia) also recognized that I was already corrupted because I had been in the night clubs since I was 13, and my school teacher did, too. But, it only takes three or four people to make a difference in your life. I lived right across the street from Garfield High School, and we played three clubs each night until 5:30 in the morning, and Parker Cook never scolded me for coming to school at 11 o'clock. He said this was what I was born to do. And I had a history teacher name Shnelling who encouraged me, also," said Jones.

He was "adopted" by many and taken under the wings of entertainers like Clark Terry, Benny Carter, Count Basie and Ray Charles who taught him Braille – all who helped mold him into the icon he is today.

Even though he had a scholarship to Seattle University, he didn't like the music program and really wanted to be back east with Charlie Parker and Dizzy Gillespie with the bebop sound. So, after receiving a scholarship to the Schillinger House of Music he went to school, but Lionel Hampton had invited him to travel with his band.

"I was sitting on that bus all day waiting. I was so excited I didn't tell anyone. They all got on the bus and then Gladys Hampton said 'Gates (the name she called Lionel), what's that child doing on this bus?' He mumbled something and then said 'I just hired him to go with the band.' She said 'Honey, get off this bus and go to school.' I was never so upset in my life," Jones said. "They said we'll get



Ted Polito (left) and Chuntelle Milton (right) are escorted by Delvin Hughley at the Be Yourself Be Beautiful Jet Set Fashion Show

Photo by Bernard Grant

back to you later, and they did. They called me when I was about 19 and I played with Hampton for three years. That was the best thing that could happen to me. We made \$17 a night."

Jones respected the older guys and took to heart what they told him and taught him. Jones said they would say "Hey young blood. There are hills and there are valleys. Hills are easy. But the valleys are where you find out what you are made of and in Black show business, no one stays on top so we help each other."



Other words of advice he has carried throughout his 76 years of life came from Ben Webster, who said, "Everyplace (country) you go, eat the food the real people eat, listen to the music the real people listen to and learn about 30 to 40 words of the language." And as a world traveler, he says he has followed that advice obediently and can speak in 14 languages, including Mandarin, Greek, Turkish, French, Swedish, Russian and Japanese.

Jones professes that he knows this country but never, never believed he would live to see a Black president in his lifetime, and said that young people helped change this world. He admits that he did not know what they – Oprah, Barack and Michelle – were up to while sitting at his kitchen table back in March 2005. But today, Jones said, "He (Barack) is working it, probably doing more than he should, but doing some things that should have been done a long time ago. He is bringing people together. That is my foundation."

Wearing a bracelet with Hindu, Judaic, Buddhist, Christian and Islamic symbols, Jones reiterated that it's all about coming together and said, "If you don't have a diagnosis, you can't write a prescription. You have to know what is wrong."

In 1985, Jones wrote the perfect prescription when he orchestrated and brought together diverse entertainers for the "We Are The World" production. "When you do things like that, you don't know if it will work or not. You try your best shot and anyone who says they know that it will work, is lying. You just have to do your best. Try to get it together on a parallel course while trying to get a list of stars which is always hard."

Under his leadership, Lionel Richie and Michael Jackson wrote the music and 46 singers spent 12 hours in the studio immediately after the American Music Awards. Jones said it was a journey but the entertainers are there for everything – always, even if it works them because voices get tired – drums and synthesizers don't. They come with the purity of heart.

"That is the reason I am so honored to be part of John Sie's efforts. Passion is not enough. You have to have infrastructure and a step-by-step-plan and details of what makes it work. It is a

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