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Changing Perceptions

When June Richard's daughter Eliza was born with Down Syndrome, the geneticist said her other two daughters would never have a friend, there would be no more family vacations, and life as the Richards knew it was over.

"I sobbed hysterically for two weeks, 24 hours a day," Richard says. "These medical professionals don't see a value of a child with Down Syndrome."

But Eliza, now 7, defied every obstacle. She was in the pool at four days old and walked at 18 months as opposed to 5 years, as doctors predicted.

Richard became involved in the Global Down Syndrome Foundation and found the information and support she needed. The GDSF is a nonprofit organization committed to improving the lives of people with Down Syndrome. Its primary focus is to support the Linda Crnic Institute for Down Syndrome, which focuses on clinical research, basic research and clinical care.

The GDSF was founded by Michelle Sie Whitten, when her daughter Sophia, 7, was also born with the chromosomal condition. Down Syndrome occurs when there are three copies of the 21st chromosome instead of two.

Again, the geneticist flooded the Whittens' heads with grim statistics on development and life expectancy. The termination rate for fetuses with Down Syndrome is 80 to 90 percent. But the couple decided to continue with the pregnancy and never looked back.

While searching for information on her daughter's condition, Whitten found fragmented, outdated information. She learned that Down Syndrome receives the least funding from the National Institutes of Health, yet it is the most common chromosomal condition. There are more than 400,000 cases in the United States and an estimated 3 million worldwide.

"What pushed me in this direction is this amazing untold and ongoing story of human and civil rights for people with Down Syndrome," Whitten says. "It opened up a whole new world of diversity to me."



Michelle Sie Whitten and her daughter Sophia

BE BEAUTIFUL, BE YOURSELF

The Global Down Syndrome Foundation will hold its second annual fashion show titled, "Be Beautiful, Be Yourself Jet Set Fashion Show," on Saturday, **October 2** at the Hyatt Regency in the Convention Center. "The best fundraisers are also awareness builders; we wanted to showcase the beauty and the brilliance," Whitten says. Last year's show raised \$1.5 million and featured jazz icon Quincy Jones and singer-songwriter Josh Kelly. For more information or to RSVP, call 303.468.6663 or email dmoore@ajsfoundation.com and visit coloradojetset.com

Whitten became devoted to changing the perception of people with Down Syndrome. "On one hand, we don't want people to feel sorry for us or our kids, but on the other hand, yes we do—human rights and civil rights aren't being afforded to our kids," she says.

Besides funding crucial research, Whitten wants to launch a Down Syndrome registry and biobank. Colorado is especially challenging, she says, because it ranks 46th in terms of services to people with intellectual and developmental

disabilities. "Knowing that you're doing the right thing and that you're on the right path is hugely satisfying and makes the hard work so much more gratifying," Whitten says.

The GDSF was officially founded in 2009, though it operated under a different name for several years prior. While under its former name, the organization began a symposium series, bringing world-renowned experts to Denver to educate both parents and physicians. Richard has attended three symposiums that focused on speech, posture and how to approach the public school system.

"The symposiums are a godsend. Knowing that I could go and hear the best in the world in their areas of specialties made me realize that I wasn't alone," Richard says. "I didn't have to spend thousands of dollars to fly across the world to see the best—I'm able to see them myself and obtain an understanding of where I need to go with my child."

Patricia Winders, physical therapist who specializes in Down Syndrome at The Children's Hospital was one of the featured speakers. She works with young children to address the three main physical issues: floppy muscle tone, decreased strength and joint hyper-flexibility. "My goal is to help them learn skills and be proactive so they develop the right movements and don't have problems that limit their independence and mobility," Winders says.

After working at the Kennedy Krieger Institute in Baltimore for 20 years, Winders moved to Denver to partner with Michelle and help the GDSF enhance the lives of those with Down Syndrome. "Michelle really inspires me in terms of the breadth of how she's looked at the issues of people with Down Syndrome and embracing how she can make a difference not only for her daughter, but for everyone," Winders says. "Whatever she's learned for Sophia, she has an equal commitment to have that available for everybody around the world. That's really why I've been so moved to change my life and be a partner on her team." D