## Michelle Sie Whitten, President & CEO, Co-Founder, Global Down Syndrome Foundation

Michelle Sie Whitten is the President and CEO of the Global Down Syndrome Foundation (GLOBAL). She co-founded the organization in 2009, after giving birth to her daughter Sophia, who happens to have Down syndrome. GLOBAL is the largest non-profit in the U.S. working to save lives and dramatically improve health outcomes for people with Down syndrome.

GLOBAL's primary focus is to advocate and fundraise for its affiliate organizations with hundreds of scientists and clinicians on groundbreaking Down syndrome research and improved medical care. GLOBAL has donated more than \$32 million to establish the Linda Crnic Institute for Down Syndrome, ("Crnic Institute"), the first Down syndrome research institute supporting over 400 scientists and over 2,700 patients with Down syndrome from 33 states and 10 countries. GLOBAL has a membership of over 150 Down syndrome organizations worldwide and is part of a network of Affiliates – the Crnic Institute, the Sie Center for Down Syndrome at Children's Hospital Colorado, and the University of Colorado Alzheimer's and Cognition Center – all on the Anschutz Medical Campus, and the Pilot Adult Down Syndrome Clinic at Denver Health.

GLOBAL's widely circulated medical publications include <u>Global Medical Care Guidelines for Adults with</u> <u>Down Syndrome, Prenatal & Newborn Down Syndrome Information</u>, and the award-winning magazine <u>Down</u> <u>Syndrome World TM</u>. GLOBAL also organizes the annual <u>Accept Ability Gala</u> in Washington DC, and the annual <u>Be Beautiful Be Yourself Fashion Show</u>, the largest Down syndrome fundraiser in the world. Visit globaldownsyndrome.org and follow us on social media <u>Facebook</u>, X, Instagram, and LinkedIn.

Working closely with Congress and the National Institutes of Health, GLOBAL is the lead advocacy organization in the U.S. for Down syndrome research and care. Michelle and her GLOBAL staff lobby Congress to ensure Down syndrome receives its fair share of funding from the federal government. GLOBAL's hard work has resulted in a quadrupling of the Down syndrome research budget at the National Institutes of Health (NIH), from \$27M in 2016 to an estimated \$133 in FY2024. GLOBAL is the largest funder of Down syndrome research and medical care after the federal government.

Michelle has received several awards for her Down syndrome work over the past decade, including: 17 ICON awards, Denver Business Journal's Most Admired CEO Award, 2 National Down Syndrome Congress President's Awards, arc Thrift Stores' inaugural Distinguished Disability Leadership Award, University of Colorado Regents Award, Western Fantasy Humanitarian of the Year Award, NEWSED Civil Rights Award, Triumphant Woman Award from the Excelsior Youth Center, the Colorado Cross Disability Coalition Award, the inaugural National Football Foundation Community Outreach Award, Rainbow of Hope Award from Keshet of the Rockies, the Developmental Pathways Frances Owens Family Involvement Award, and the Arc Thrift Community Leadership Award.

Michelle sits on the boards of arc Thrift Stores of Colorado and the Linda Crnic Institute for Down Syndrome, She and GLOBAL have been asked to speak at numerous conventions on Down syndrome advocacy, including the United Nations Headquarters and the Mission of the Holy See for the last several years. Prior to her career in the non-profit sector, Michelle was a cable TV pioneer in East Asia working for Liberty Media Corporation and Starz Encore. She worked in the cable industry from 1993 until 2005 and is considered a pioneer in the China media industry. For her work during that time, she received the 40 Under 40 Achievement Award, the Real Women: Outstanding Entrepreneur Award, and the Women in Cable & Telecommunications Walk of Fame Award.

Michelle's academic career focused on international security and diplomacy. She holds a Master of Arts degree in Regional Studies – East Asia and a Graduate Certificate in Business Administration, both from Harvard University. She studied Mandarin Chinese at Peking University and graduated magna cum laude with a Bachelor of Arts degree in Asian Studies from Tufts University.

Michelle is married to Tom, a British curator of Chinese contemporary art and they have two children, Sophia and Patrick.