



WOMEN IN RARE

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5 JUNE 2025



🕒 Estimated reading time: 0 minutes



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My career has a complex intersection of diversity, equity and inclusion (DEI), corporate strategy, marketing, advertising and change management. As a servant leader, I’ve held leadership roles in both the private and non-profit sectors, demonstrating a commitment to addressing disparities and fostering inclusive growth.

At Turner, the broadcasting company, my role as the corporate leader advanced the DEI initiatives to be award-winning, ensuring that marginalised communities had a voice in corporate decision-making. I have also led strategic advertising efforts that amplified diverse narratives and drove impactful change.

Most recently, I’ve contributed to the Rare Disease Diversity Coalition, focusing on reducing health disparities and improving outcomes for underserved patient populations. With expertise in strategic planning, stakeholder engagement and policy advocacy, I’ve been a key driver of initiatives that promote equity and access across industries.

What motivated you into your chosen career path?

My career path has been shaped by my family background in healthcare—both my parents as doctors and several other close relatives as well, a deep love for learning about other cultures, and an innate passion for helping others.

Growing up in a household where healthcare was a constant conversation, I developed an early appreciation for how paramount health is in life and the critical role prevention plays in overall wellbeing.

This, combined with my curiosity about diverse communities and global perspectives, fuelled my drive to address disparities through strategic initiatives. Earlier in my career, I co-wrote the Diversity and Disparities Plan for the American Cancer Society, solidifying my commitment to addressing health inequities. My experience in advertising, change management and corporate strategy has allowed me to blend creativity with impactful advocacy.

More recently, my work with the Rare Disease Diversity Coalition (RDDC) has deepened my dedication to improving health outcomes for underserved populations. By bridging cultures, industries and policies, I strive to create lasting, meaningful change that fosters true equity and inclusion.

What do you see as some of the opportunities as a woman in your field?

Women in rare diseases and health equity have the opportunity to drive bold, transformative change in healthcare, both locally and globally. Despite women making up only about 33% of global researchers and 28% of the STEM workforce in the US, the gender gap presents a unique opportunity for women to lead in shaping equitable healthcare solutions. This underrepresentation opens doors for women to step into leadership roles where they can influence public health policies and address disparities that impact marginalised communities worldwide.

In patient advocacy organisations, women hold leadership positions that amplify patient voices and drive healthcare policies. About 40% of non-profit organisations, including those focused on health equity and rare diseases, are led by women, positioning them to raise awareness and advocate for policies that address global healthcare disparities.

Furthermore, women are leading entrepreneurship and social innovation efforts that bring systemic change. From developing digital health tools and telemedicine platforms, to advancing biotech solutions, women are breaking barriers to increase access to healthcare in underserved regions.

In South America, where healthcare access can be limited, women are at the forefront of creating innovative solutions that improve communication between patients, caregivers and healthcare providers, ensuring better disease management and prevention.

By leading in entrepreneurship and innovation, women help create a more inclusive and just healthcare system that addresses the needs of diverse populations. Their leadership fosters collaboration across sectors and ensures that healthcare policies are shaped with equity in mind, promoting access to care regardless of geographic location, socioeconomic status or background. Women in rare diseases and health equity can influence and make a lasting impact on healthcare for all.

What are some of the barriers to success as a woman in your field?

Women in the rare disease and patient advocacy sectors face numerous barriers to success, compounded by cultural norms, gender bias and systemic inequalities.

- 1) In the patient advocacy space, although 40% of non-profit organisations are led by women, gender bias often leads to their voices being marginalised in decision-making processes. This cultural barrier limits women’s influence in shaping healthcare policies that could improve access for rare disease patients in underserved communities.
- 2) The gender gap in leadership is further exacerbated by the lack of mentorship and networking opportunities for women, hindering their career growth.
- 3) In research leadership, men dominate senior positions and receive a disproportionate share of funding, with women-led research receiving only 15% of all research grants. This underfunding stifles critical innovation and limits the progress needed to address rare diseases, especially in underserved populations.

What is one piece of advice you would give your 10-year-old self?

To my 10-year-old self I would say, “Use humour to make friends, throw off your enemies and connect with new people. Don’t be afraid to speak up, even when others may doubt you.

Trust your unique perspective and recognise that your experiences give you a special role in bridging communities. Cultivate your confidence, knowing that you are capable of leading change.

Remember, boldness comes from staying true to yourself and your values. As a role model, you’ll inspire others to do the same. Keep pushing forward; everything will be alright as you have built up your network while always being your kind and authentic self.”

Can you tell us about your current work priorities and focus or a particular project you are working on?

RDDC works to eliminate health disparities for historically marginalised rare disease patients by developing and deploying evidence-based advocacy tools and research interventions. Our efforts aim to improve the health outcomes of diverse rare disease patients worldwide. The Coalition operates with three active working groups focused on: 1) Representation in clinical trial research, 2) Government regulation, legislation and policy, and, 3) Patient, provider, caregiver diagnostic and living journey. Each group has specific priorities designed to create systemic change in healthcare.

1) **Clinical trials:** A sub-working group co-wrote a comprehensive review of the Rare Disease Clinical Resource Network (RDCRN)—diversity demographics data collected over 20 years from NIH clinical trial sites. This review offers critical insights into the representation of diverse populations in rare disease trials, addressing trends and gaps. It has been sent to journals for publication.

2) **Policy:** The policy workgroup has focused on building relationships with congressional leaders across both parties to advance policies for rare disease patients. With growing influence, RDDC contributed to the creation of the Health Equity and Rare Disease (HEARD) Act, led by representative Marilyn Strickland. The act aims to increase investments in rare disease research for minority populations.

3) **Patient-driven research:** RDDC has partnered with the Rare Genomes Project at the Broad Institute of MIT and Harvard to lead a patient-driven research study. This study, focused on genomic sequencing for rare and undiagnosed conditions, is currently ongoing, and the genetic data will be shared to maximise impact across the scientific community.

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