

The Medical "Standard of Care" Perspective Toward Rare Disease and Terminal Illness

Presenter: Sarita Edwards, BHSc

Abstract: The medical perspective sets the standard of care model for all medical diagnoses; even those lacking a continuation of research to further explore possible alternative outcomes. What happens when a medical diagnosis falls within the scope of rare disease or terminal illness? Often, due to research inadequacies or inefficiencies toward treatment development, the medical perspective's 'standard of care' model lacks the necessary data to explore alternative solutions. Patients are therefore forced into streamlined medical models created for standard solutions, not individualized care.

Takeaways:

- Standard of care models lack research development as it often relates to rare disease and terminal illness.
- Patients are forced into a 'standard practice' medical mold that may not directly relate to solution options for their medical diagnosis.

- Advancements in research and education can improve the medical perspective toward rare disease and terminal illness.

Biography:

Sarita Edwards is CEO & President at the E.WE Foundation, a 501(c)(3) healthcare advocacy organization. She began her efforts of advocacy and public policy after receiving a diagnosis of rare disorder Edwards Syndrome or Trisomy 18 for her unborn child. Sarita is recognized as a world's top patient expert and social media ambassador; and, host of the Being Rare Podcast, an online resource hub and community conversations platform most known for its 60 second episodes.

Sarita serves on executive boards for other nonprofit and community organizations. She is a rare disease legislative advocate, a member of multiple coalitions promoting health & racial equity, and serves as a Community Congress member providing advice and insight on urgent policy initiatives. Sarita serves on advisory councils within her home state and across the country and participates in DEI workgroups on race, disability, and genetic education.

Sarita has a Bachelor of Science in Health Science from Athens State University and more than 20 years experience in Healthcare Operations & Administration. She also has continuing education studies in effective parenting, childhood behavior, and childhood abuse & neglect. Sarita lives in Alabama with her husband Kareem and their five children.

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