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Patient-directed insights on the evolution of treating rare genetic diseases

In the Western world, we have a tradition of describing disease as something that must be fought and destroyed. This poses a problem for people with rare genetic diseases, as these conditions cannot exist outside the individuals affected by them. Health care providers must instead approach these patients with a humanist goal: supporting their patients to thrive. We present four themes elucidated from web-based surveys of people affected by sickle cell disease: 1) recognizing patients as subject matter experts in their own right, 2) moving beyond disease awareness to compassionate allyship, 3) broadening our scope of understanding to include chronic and cumulative damage associated with genetic disease, 4) supporting patients' interest in clinical studies and clinical trials. By providing a protected space for 160 patients to express their own views, we uncovered themes and recommendations relevant to the broader rare disease community. These revelations can guide people living and working at all points on the researcher-provider-patient continuum as we globally move toward a more personalized approach to modern medicine.

Biography

Mattie Robinson, MS MA was awarded graduate degrees from Johns Hopkins University and the University of Florida. Ms. Robinson has over 7 years of biomedical research experience in Human Genetics and Molecular Biology, Microbiology, and Chemistry. She is the President of Micromattie Consulting Inc., a firm specializing in amplifying the patient voice in rare disease research and clinical practice. Previous clients include large medical centers, early-stage pharmaceutical companies, professional organizations, and US-based regulatory agencies. Micromattie Consulting Inc. serves as a guide and liaison to ensure that new therapeutic developments align with patient needs.

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