

Abstract Title: National Rare Disease Policy, its implication on healthcare delivery and research support in India

Author Name: Mr. Saurabh Kr. Singh, Chairman

Author Institute: Rare Diseases India Foundation, Delhi NCR, India

Abstract: Saurabh Singh serves as the Co-Founder and Chairman of the "Rare Diseases India Foundation" (RDIF), dedicating more than nine years to actively championing the cause of rare diseases. Through his extensive efforts, he has played a pivotal role in raising awareness about rare diseases in the country and has been a key advocate for the development of a National Rare Disease Policy in India. Saurabh, with PGDBA under his belt, boasts a professional background spanning over 14 years in various multinational companies.

Beyond his corporate achievements, Saurabh holds an NCC "C" Certificate and has received recognition from notable figures, including the Hon'ble Prime Minister of India in 2000, the Governor of Bihar in 2000, the Union Health Minister, the Health Minister of Jharkhand, the Governor of Jharkhand in 2022, and several Members of Parliament. His commitment to the cause of rare diseases is deeply personal, as his own son grapples with MPS II, one of these uncommon conditions.

Saurabh has not only advocated for an effective Rare Disease Policy but has also garnered multiple awards for his contributions to the field of rare diseases on various platforms. His multifaceted experience and dedication underscore his significant impact in the realm of rare diseases in India.

Area of expertise: Advocating Rare Diseases