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Society and government join forces to address over 200 rare diseases in Egypt



The National Association for Rare Diseases (NARD) organised a scientific forum on occasion of World Rare Disease Day, in coordination with the friends of Abu El Reesh Children's Hospital and Novartis Pharma Egypt. Renowned haematology experts, as well as representatives from the Ministry of Health, armed forces hospitals, and the Central Administration for Pharmaceutical Affairs discussed improving the lives of rare disease patients in Egypt.

For the first time in its history, the Qasr El-Aini hospital building was lit in the three colours representing rare diseases—green, blue, and pink—demonstrating its commitment to providing affected patients with the medical, social, and moral support needed. Nearly 400 million patients around the world are affected by rare diseases.

Dr. Neveen Soliman, professor of pediatric medicine at Cairo University and NARD founder, emphasised

NARD's commitment to raising awareness of rare diseases and collaborating with partners—including the National Research Centre, the Health Insurance Organization, armed forces hospitals, society organisations, the media, and pharmaceutical companies—to improve the quality of healthcare and community services provided to rare disease patients.

"Our first objective is to highlight rare diseases, in terms of awareness, diagnosis, treatment, and statistical prevalence to help us provide patients with access to effective treatments. Every year the conference focuses on a particular value and this year we shed light on the critical role of medical research," Dr. Soliman said.

"Participants discussed establishing a rare diseases centre encompassing relevant authorities to improve patient conditions and create a registry to help ensure the availability of the most effective treatments," Dr Soliman added.