NARD
National Association for Rare Diseases
الرابطة القومية للأمراض النادرة

NOVARTIS

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Cairo conf. tackles rare diseases

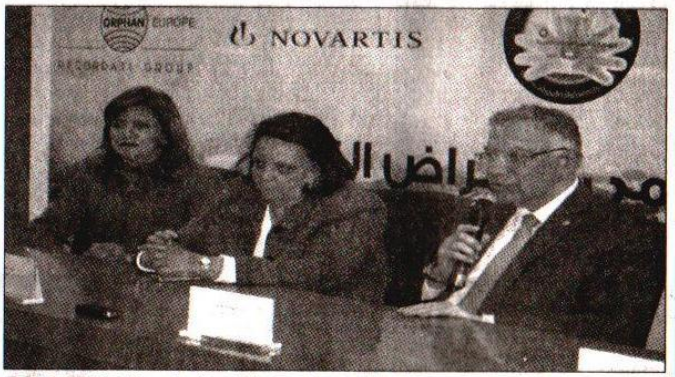
HELPING to raise awareness about rare diseases, Qasr el-Ainy hospital was brilliantly illuminated in green, blue and pink lights as a part of the activities surrounding a recent conference taking place on World Rare Diseases Day. The display demonstrated the hospital's commitment to providing the medical, social and moral support needed to patients who are suffering from uncommon maladies, as organised in association with the National Association for Rare Diseases (NARD), the Friends of Abu El-Rish Children's Hospital, the Armed Forces hospitals and a major pharmaceutical company.

Dr Neveen Soliman, Professor of Paediatric Medicine at Cairo University and the NARD's founder, emphasised the association's commitment to raising awareness about rare diseases in order to improve the quality of healthcare to these patients, in collaboration with the National Research Centre, the Health Insurance Organisation, the media and pharmaceutical companies.

NARD aims at highlighting rare diseases, in terms of awareness, diagnosis, treatment and statistical prevalence, to provide patients with access to effective treatments, Dr Soliman said, stressing the essential role played by medical research in this field.

A "rare" disease is defined as affecting one patient in 2,000 to 2,500 people, said Dr Hafez Bazraa, Professor of Paediatric Medicine at Cairo University, noting that the real challenge patients face is the high cost of drugs compared to treatments of other, more common ailments.

He added that there are 200 to 300 kinds of rare diseases in Egypt that can affect the kidneys, liver, nerves and many other organs; therefore, patients have every right to receive effective medications. "The lack of medical and community awareness of such diseases, in addition to the similarity of their symptoms to more widespread illnesses, is contributing to delaying diagnosis and treatment," stated Dr Bazraa.



DR SHERIF Naseh (1st R), Dr Magda Badwi and Dr Neveen Soliman stressed the NARD's support for patients with rare diseases during a conference held recently on the occasion of World Rare Diseases Day.

One such rare paediatric diseases discussed was tuberous sclerosis complex (TSC), which is a genetic disease that causes benign tumours to grow in the brain and on other vital organs, such as the kidneys, heart, liver, eyes, lungs, and skin. "A combination of symptoms may include seizures, intellectual disability, developmental delay, behavioural problems, skin abnormalities, and lung and kidney disease," stated Dr Marianne Youssry, Professor of Paediatric Medicine at Cairo University.