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Annual Rare Disease Day marked

KASR Al-Aini School of Medicine marked its 3rd annual World Rare Disease Day at Mounira Children's Hospital. It was attended by patients and their families, doctors and a number of charitable organisations.

The event emphasised the ongoing work to raise awareness of these diseases so as to help improve strategies and policies related to rare diseases at the national level.

Dr Neveen Soliman, Professor of Pediatrics at the Kasr Al-Aini School of Medicine and Head of the National Association for Rare Diseases (NARD), spoke of the importance of acquiring the most advanced diagnostic and treatment techniques for rare diseases.

Patients with rare diseases, she pointed out, have as much right to be treated as do those who suffer from more common disorders.

"A disease is considered rare if it affects only about one in 2,000 people. Some 30 million people worldwide suffer from a rare disease. About 80 per cent of these disorders are attributable to genetic troubles, while viral or bacte-

rial infections, allergies and environmental factors are responsible for 20 per cent of the incidence rates," Dr Ahmed el-Beleidy, the Head of the Pediatric Medicine Department at Kasr Al-Aini School of Medicine.

About 50 to 60 per cent of those suffering from rare diseases are children, which is the reason for the Pediatric Medicine Department's support for rare disease patients and the great efforts undertaken in this regard, he added.

"Even though rare disease patients and their families have faced numerous challenges, there have been significant, positive developments in this issue over the past few years," Dr Hussein Khairy, the Head of the Doctors' Association said.

"The implementation of a number of comprehensive rare disease strategies has led to the ratification of general health laws and policies.

"The Abul Rish University Hospital is an example of a hospital in which progress has been achieved in terms of diagnosing and treating these diseases, and we hope that this will be replicated in all hospitals."



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