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Commemorating world diseases at Al-Qasr Al-Eini for third year in a row

To mark the occasion of the World Rare Disease Day, Al-Qasr Al-Eini Hospital held its third annual celebration at the Mounira Children's Hospital, entitled "Inspirational hearts and minds". The celebration brought together patients and their families with the professors, fellow researchers, doctors, nurses, employees, patient support groups, medical students, the media and charitable organisations.

Moreover, it aimed to highlight the importance of ongoing cooperation towards a better future for patients suffering from rare diseases. The strong support for the event reflects the increasing awareness of these diseases, which in turn will help improve strategies and policies related to rare diseases at the national level.

At the start of this year's event Neveen Soliman, professor of Paediatrics at the Cairo University and head of the National Association for Rare Diseases (NARD) explained that World Rare Disease Day is a day of awareness celebrated at the end of February of every year. She noted that this year's celebration was initiated by the NARD to increase local awareness of rare diseases and support the families affected, and to emphasise both the importance of making the best diagnostic tools and treatments available, as well as the fact

that rare disease patients have as much right to treatment as those who suffer from more common disorders.

"A disease is considered rare if it affects only about 1 in 2,000 people. Thirty million people worldwide suffer from a rare disease, with 80% of these disorders having a genetic basis, while viral or bacterial infections, allergies and environmental factors are responsible for 20% of incidence rates," explained Ahmed El Beleidy, head of the Paediatric Medicine Department at Cairo University. He added that 50% to 60% of those suffering from rare diseases are children and confirming the Paediatric Medicine Department's support for rare disease patients and the great efforts undertaken in this regard.

"On this day, we seek to increase society's awareness of rare diseases to counteract the self-imposed isolation of rare disease sufferers and their families, and allow them to live normal lives," explained Khaled Makeen, faculty deputy for Community Service Affairs and Environmental Development at Cairo University.

"Joint civilian and governmental efforts can help these patients overcome this self-imposed seclusion, and we are committed to providing the genetic testing necessary for rare disease at all Al-Qasr Al-Eini hospitals in the near future," he added.



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