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On 8th International Rare Disease Day:

30% of myelofibrosis cases develop into leukaemia or myeloma

Egypt's Central Administration of Pharmaceutical Affairs (CAPA), together with Novartis Pharma Egypt SAE, held a scientific forum on occasion of the 8th annual Rare Disease Day, organised by the World Health Organization (WHO). Themed "How to Live with a Rare Disease?", renowned haematology experts raised patients' and their families' awareness on treatment and coping methods for these rare illnesses. They also focused on myelofibrosis; a rare illness, but with substantial impact on patients.

"Myelofibrosisis a rare, acquired (ie non-hereditary) disease that occurs as a result of marrow cells being replaced with scar tissue," said Mervat Mattar, Professor of Haematology at Cairo University. "This leads to failure to produce sufficient blood cells, an enlarged spleen, anaemia in affected patients, as well as a white blood cell and blood platelet deficiency. Symptoms include exhaustion, stomach pain and pain under the ribs, as well as muscle and bone aches and early satiation causing rapid weight loss."

She highlighted the lack of statistics on disease prevalence in Egypt, due to lack of research and awareness as well as disease rarity. "The median age range for myelofibrosis patients is 50-60, whereas in Egypt the disease strikes patients at a substantially younger age, between 20 and 30," said Mattar. "Early diagnosis and treatment is crucial given that one third of bone marrow fibrosis cases develop into severe leukaemia or myeloma."

Mahmoud Diaa, Head of Hospital Pharmacology at the Ministry of Health said: "Unfortunately myelofibrosis is often diagnosed at a very late stage, because of lack of awareness and widespread occurrence of spleen enlargement in Egypt due to the high prevalence of schistosomiasis (bilharzia) and HCV. This often leads to a misdiagnosis - with the disease only correctly identified after one or two years - as patients visit internal medicine or hepatology specialists, instead of haematology specialists."

He said the day was an opportunity to emphasise the importance of joint government and civilian efforts to raise awareness of myelofibrosis among both the medical community as well as the general public. "If an accurate diagnosis is made early, a patient can quickly begin treatment which helps prevent the disease from advancing and enables patients to live a normal life," he added.