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Living with a rare disease

HOW to live with a Rare Disease is the theme of a forum held on the occasion of the eighth annual Rare Disease Day organised by the World Health Organisation (WHO) in Cairo. During the forum, renowned hematology experts raised the awareness of patients and their families with regard to treatment and coping methods that apply to rare conditions. They also focused on Myelofibrosis; a rare illness which has a substantial impact on patients.

"Myelofibrosis is a rare, acquired (i.e. non-hereditary) disease that occurs as a result of marrow cells being replaced with scar tissue," said Dr Mervat Mattar, Professor of Hematology at Cairo University. "This leads to failure to produce sufficient blood cells, an enlarged spleen and anemia 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 the disease's 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 Dr. Mattar. "Early diagnosis and treatment is crucial given that one third of bone marrow fibrosis cases develop into severe leukemia or myeloma."

Dr. 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 the widespread occurrence of spleen enlargement in Egypt due to the high prevalence of Schistosomiasis (bilharzia) and Hepatitis C Virus (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 hematology specialists."

He said the Rare Disease Day was an opportunity to emphasise the importance of joint government and civilian efforts to raise awareness of Myelofibrosis among both the medical community and 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.