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Flim sheds more light on Thalassemia

THE first documentary film on the lives of patients with thalassemia was screened at the Al-Sawy Culture Wheel and organised by the Egyptian Thalassemia Association (ETA), marking World Thalassemia Day and raising awareness of the disease.

Considered one of the most dangerous genetic illnesses, Thalassemia is an inherited blood disorder in which the body makes an abnormal form of haemoglobin. The disorder results in excessive destruction of red blood cells, which leads to anemia. Thalassemia is inherited, meaning that at least one parent must be a carrier of the disease.

The documentary film dealt with the life stories of two female patients with thalassemia; Heba Ibrahim and Manal Shoukri.

According to Dr Amal el-Beshlawi, professor of Hematology and Pediatrics at Aboul Rish University Hospital and Head of the ETA, the reason for screening the documentary film was to send a message of hope to patients with thalassemia in Egypt, whose number has reached around 30,000 cases.

She added that documentaries are part of a global programme highlighting stories of patients with thalassemia and their treatment opinions that depend on blood transfusions. In addition, the programme is based on raising awareness of a treatment for thalassemia that depends on decreasing iron in blood and highlighting challenges in patients' daily lives, she added.

Heba Ibrahim, a 26-year-old female patient with thalassemia featured in the documentary, noted that she was diagnosed with the disease in her first year of her age. "As a child, co-existence with the disease and receiving the treatment was not an easy matter. I learnt so much from other patients with thalassemia, so I appeal to the necessity of creating new channels to exchange information among patients," she said. She also urged that, as

the disease is hereditary, pre-marriage check-ups should become mandatory and consulting centres should be set up to inform those who want to get married of disease, as well as cases of inter-familial marriage, which increases the chances of having the disease.

Manal Shoukri, the other thalassemia patient in the documentary, stressed the necessity of understanding the disease to be sure that children and adults get the health care they need. She added that she is a volunteer at the Egyptian Red Crescent to inform patients and their families about the disease, stressing that patients could live a better life through treatment.

Dr el-Beshlawi stated that thalassemia has been controlled due to new medications that are received orally to help decrease iron levels in blood.

These drugs turned this disease from a fatal into chronic and are improving the quality of life. The new drugs, such as deferasiroi, are the first medicine taken by mouth with low side effects, instead of via injections under the skin.