

Shanghai sets up medical aid fund for treating rare diseases

A fund for assisting the medical treatment of patients with rare disease was initiated in Shanghai Sunday.

The fund with starting money of 3 million yuan (US\$435,000) was jointly raised by rare disease prevention and treatment institutions in Shanghai and drug firms such as Sanofi.

Li Dingguo, chair of the Shanghai Rare Disease Prevention and Treatment Fund, said that the funding would encourage more effective prevention and medical treatment of rare diseases.

He said the fund would help pool more financial support and company donations for rare disease patients.

“The fund will be primarily used for improving medical treatment for lysosomal storage diseases, which contain some 50 rare diseases of inherited metabolic disorders,” Li said.

Globally, there are some 6,000 to 7,000 recognized rare diseases. Only a few of them have established medical treatment, such as Gaucher Disease and Pompe Disease.

About 60 percent of rare disease patients are children, with 30 percent living less than five years.

Li said there has been no epidemiological survey of rare disease patients made in China.

“Early diagnosis and treatment can effectively check on the progress of rare diseases and even cure them,” said Zhang Huiwen, a doctor with the Xinhua Hospital affiliated with Shanghai Jiaotong University.

She said that it could take years for doctors to diagnose a rare disease, while patients miss the best time for treatment and suffer from inflicted problems leading to mental difficulties, heart problems and atrophied muscle.