

Boy suffers from life-long genetic condition

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KOTA KINABALU: Despite being at a tender age of 11, Kenny Sim Yi Hau cannot play or run like any other children for fear of getting hurt, or worse, fear of bleeding.

The reason? Kenny suffers from a severe form of haemophilia, which causes internal bleeding in his ankles and joints.

Haemophilia is a life-long genetic condition that prevents blood from clotting properly due to the lack of clotting factor. In Kenny's case, he is suffering from a deficiency of clotting factor VIII. Patients like Kenny require transfusion of factor VIII when his condition worsens.

His mother, Chin Mei Ling, realised that her son has haemophilia when he was in Primary Two, as he bled often and complained of pain.

Chin has a family history of haemophilia - her brother and uncle are both haemophilia

patients.

Due to his deteriorating condition, Kenny is confined to a wheelchair since last year. He also misses classes at his school, SRK (C) Chi Hwa Sandakan, as he cannot climb the stairs leading to his classroom at the fourth floor.

"He cannot go to school, he cannot stand because his feet are swollen due to internal bleeding," she said at a press conference at Universiti Malaysia Sabah (UMS) here yesterday.

Although medical fee is free as Kenny patronizes the government hospital, Chin lamented the lack of factor VIII concentrate.

"Kenny will complain of pain two days after his factor VIII transfusion, but the hospital does not give me too much of it because it is expensive and they lack supply."

To prevent her son from

getting hurt and from bleeding, Chin makes sure Kenny stays mostly in his room or watches television.

"I ask him not to wander here and there because I am afraid of him falling down or bumping into things." Kenny's elder sister, Kelly Sim Yi San, 13, has yet to be checked for haemophilia. Due to his condition, Chin has to quit her job to look after Kenny full time, while father Sim Nyuk Vui works as a driver.

Nonetheless, Chin is sometimes reassured that Kenny's classmates would help him carry his bag at school.

"Some of his classmates take care of him. They would help him carry his bag because they understand his condition." Kenny is the selected haemophilia patient to undergo treatment at Hospital Kuala Lumpur from May 29 to June 3 under

a collaborative clinical venture between UMS and the National Blood Centre in Kuala Lumpur.

Meanwhile, senior lecturer of the Haemostasis Laboratory at the UMS School of Medicine, Dr A Thiruchelvam, said factor VIII concentrate is not only expensive, but also inadequate in Malaysia. A treatment usually takes around five to seven days. "Considering Kenny weighs 40 kilogrammes, he needs two vials, three times a day. "One vial costs RM400, amounting to around RM2,000 a day." Thiruchelvam further said haemophilic patients carry the risk of bleeding in the brain, which can be fatal.

Hence, they have to keep factor VIII concentrate at home for emergencies.

Deputy dean of the School of Medicine, Associate Prof Dr Muhammad Tauffik Md Noor, pointed out that parents

sometimes face a dilemma whether to let their children go outdoors and mix around.

Tauffik, who is the project leader of 'A Life Without Wheelchair, Kenny! - A Haemophilia Patient', said preventing haemophilia children from going out is not healthy for them.

He stressed that sports are important for children, and suggested non-contact sports for haemophilic patients, such as swimming.

Tauffik also urged the public to seek professional treatment from doctors if they suffer from swelling in joints to obtain diagnostic.

"We have a UMS Polyclinic at Kingfisher.

"If you really have haemophilia, subsequent management can be done, such as factor VIII transfusion." Also present was UMS deputy vice chancellor Prof Dr Rosnah Ismail.



Kenny and his parents Sim Nyuk Vui and Chin Mei Ling.