

Sabah ambitious to hit zero Thalassaemia Major cases target by 2030

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Members of the society and a team from UMS taking a photo with a donor in a recent blood donation drive.



Among the individuals who were generous to donate their blood for the benefit of Thalassaemia Major patients.

For over 15 years, Sabah Thalassaemia Society had continuously educated the public about Thalassaemia, one of the most common blood diseases in the Mediterranean, South Asia, South East Asia and Middle East.

Yet today, Sabah remains number one in Malaysia with the highest number of Thalassaemia Major cases with 1,788 patients so far this year, an increase from last year's 1,698.

Notwithstanding the difference in figures compared to those in the Peninsular which stands at over 600 cases, Sabah remains ambitious with its vision to reach zero Thalassaemia Major cases by year 2030 – five years ahead of the national target of 2035.

The goal, said President Francis Mujim, is nowhere near easy but with strong collaboration and a strategic planning, the society firmly believes the target is attainable.

"Sabah Thalassaemia Society basically has two main roles – to help the government reduce the rate of Thalassaemia Major in Sabah and at the same time, to protect, develop and strengthen the quality of lives of Thalassaemic patients to the extent that they no longer feel alienated in a society.

"These patients, aside from their health condition, are just as talented as we are. I know a few patients who are now studying in universities, be it in Biochemistry, Psychology or Education.

"The eldest patient in Sabah is currently a 46-year-

old teacher; it shows that life span is no longer an issue – it relies on the person's discipline in looking after himself, and when people ask me whether patients can get married, I said yes, as long as (their significant others) are not carriers," he said.

Thalassaemia is a hereditary blood disorder that interferes with the formation of red blood cells – haemoglobin – which carry oxygen around the body. For Thalassaemia Major patients, the inability to produce sufficient haemoglobin leads to Anaemia, resulting in the need for continuous blood transfusion.

However, regular blood transfusion will lead to a build-up of iron and eventually affect other parts of the body including the heart and liver. In this case, iron chelators are required to remove excess iron from patients' blood.

These chelators can be taken orally (Exjade) or through an injectable chelator (Desferal).

"Thalassaemia Major patients have to inject the desferal using a pump for at least 10 hours a day, six days a week; the process is painful as the medication is administered during sleep, which means that they sleep with a needle stuck into their body almost every night, for life.

"Now with technology advancement, patients could take the Exjade, a dispersible tablet which has the exact same function. However, it costs much higher than desferal," said Francis.

One box of Exjade, he said, costs between RM1,200 to RM2,225 with the dosage de-

pending on doctors' advice (one to three tablets a day) compared to a bottle of desferal that costs RM20 which is required daily.

Although some of the medications are provided by government hospitals, patients need to bear RM2,500 for the desferal pump machine. In such cases, he said Sabah Thalassaemia Society continuously looks for sponsors.

Prioritizing underprivileged patients, he said, the families are required to pay as much as they could afford with hope that the machine will be taken good care of.

"The machines used to be given for free but they usually end up being returned due to improper maintenance as patients got them at no cost. Since we charge them for the machine, we had received less complaint," he said.

As Thalassaemia Major patients require costly and life-long treatment, Francis stated while one could not run from genetic factors, prevention is imperative and this could be done through screening and continuous awareness campaigns.

He stressed on the importance of screening in choosing one's life partner while for married couples who are both carriers, prenatal testing (which costs around RM1,200) in the first trimester is crucial to determine whether their child is normal or has Thalassaemia Major.

If the result shows the child to be another sufferer, doctors will give them a choice to either continue or stop the pregnancy – a dilemma which could have been prevented

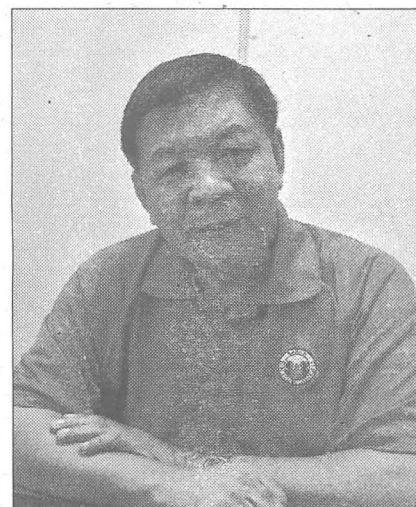
should the couple undergo screening before tying the knot.

Over the last 10 years, Francis asserted that the society had conducted numerous campaigns to educate the public and raise awareness on the importance of screening; the time has come to go deeper and be closer with the people.

"Starting next year, we are strategising by focusing on groundwork. Realising our lack of funding, we are thinking of setting up volunteers in every village to create awareness from the grassroots level.

"We will train them to

become the eyes, ears and mouth of Thalassaemia in their respective villages. This way, we don't have to go to every part of Sabah because our volunteers could reach



President of Sabah Thalassaemia Society, Francis Mujim.

out in their areas," he said.

The endeavour, he said, requires time and solid funding – both of which are limitations for Sabah Thalassaemia Society. However, he believed with active participation from the public, strong collaboration with other bodies as well as well-planned executions, the targeted zero Thalassaemia Major cases is achievable even before reaching year 2030.

"We are conscious of our limited financial resources but nonetheless, we will give all that we have to attain that goal. It

is our greatest wish to wake up in the morning of year 2030 with the realisation that no child is born and diagnosed with Thalassaemia Major," asserted Francis.