

Thalassemia in Sabah: Why every couple should screen before marriage

BY DR MELVIN EBIN BONDI ON JUNE 29, 2026, MONDAY AT 5:02 AM



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LOVE is often described as blind, but when love begins to move towards marriage, pregnancy and family planning, health should never be left in the dark. In Sabah, this message carries special meaning because thalassemia remains one of the

most important inherited blood disorders affecting families. It is not caused by infection, poor diet, lifestyle or bad luck. It is passed from parents to children through genes, often silently, long before a couple realises that their future child may be at risk.

Thalassemia affects the body's ability to produce normal haemoglobin, the protein in red blood cells that carries oxygen throughout the body. Many people who carry the thalassemia trait live healthy lives and may never know that they are carriers. This is why the condition can remain hidden within families for years. The problem usually becomes visible only when two carriers have a child together and the child inherits a severe form of the disorder.

Globally, the World Health Organization (WHO) has reported that a significant proportion of the population carries genes linked to haemoglobin disorders, including thalassemia. In Malaysia, thalassemia is the most common inherited blood disorder, with thousands of registered patients recorded through the national registry. Sabah continues to carry one of the heaviest burdens in the country. Reports from the Malaysian Thalassaemia Registry have consistently placed Sabah among the states with the highest number of registered thalassemia patients, while local screening studies have also shown that carrier rates may be especially high in some communities.

This is why thalassemia screening should not be treated as an optional matter that only becomes relevant after marriage or during pregnancy. It is a simple but powerful act of prevention. Screening can start with a full blood count, which may detect warning signs such as small red blood cells. Further tests, including haemoglobin electrophoresis, can provide a clearer picture of a person's haemoglobin status. For couples, knowing this information early allows them to seek genetic counselling, understand their risk and make informed decisions before starting a family.

When both parents carry relevant thalassemia traits, each pregnancy may carry a 25% chance of having a child with thalassemia major. This is not a small risk when the consequences can shape the whole life of a child and family. Children with thalassemia major often require regular blood transfusions and iron chelation therapy. They may also face complications affecting growth, energy levels, organ function, school attendance, emotional wellbeing and family routines. Treatment can be lifesaving, but it also demands long-term commitment from parents, caregivers and the health system.

Dr Annie Alfred, Doctor of Public Health candidate at Universiti Malaysia Sabah (UMS), emphasises that thalassemia screening should be normalised before marriage because many carriers remain healthy and unaware of the genetic risk they may pass to their children. Dr Rahimah binti Rasali, Doctor of Public Health candidate at Universiti Malaysia Sabah (UMS), highlights that early screening gives couples the opportunity to seek counselling, understand their reproductive risks and make informed decisions before starting a family.



Dr Rahimah binti Rasali

For many families, the burden is not only medical. Regular hospital appointments, transport costs, time away from work and the emotional strain of lifelong treatment can slowly become part of daily life. In rural and interior communities, these challenges may be even heavier because access to specialist care is not always easy. This is why prevention through early screening must be seen as a public health priority, not merely a personal decision between two people.

In one Sabah study involving parents of children with transfusion-dependent beta-thalassemia major, most parents had not undergone premarital screening, and many were unaware of their carrier status before marriage. This finding is painful because it shows that many families were not refusing prevention. They simply did not have the information early enough. The lesson is clear. Awareness must reach young people before marriage, before pregnancy and before difficult decisions have to be made under pressure.

Malaysia has already taken important steps through school-based screening, antenatal screening, cascade screening among family members and voluntary screening. These efforts must continue, but they also need stronger community acceptance. Screening should not be seen as a threat to love, marriage or family honour. It should not be viewed as a reason to shame anyone or to label a person as unsuitable for marriage. A carrier is not sick, weak or flawed. A carrier simply carries information that matters for the next generation.

In this sense, thalassemia screening is not about stopping people from loving each other. It is about helping couples love responsibly. It gives them the chance to understand their options, seek counselling and prepare wisely. Some decisions may be difficult but making them with knowledge is always better than facing the consequences in silence. For Sabah, the message must be direct. Before love becomes family, know what your blood carries. A simple blood test can protect future children from a lifetime of treatment. It can spare families from preventable suffering. Most importantly, it turns love from a feeling into an act of responsibility. The greatest gift we can offer the next generation is not only affection, but foresight. To screen is not to doubt love. It is to protect it.