

# Restoring the 'Sight' of a Nation

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Above: The land locked district of Ermera.

## Life in Letefoho

Rafael De Jesus lives in Letefoho, Ermera, one of the two land-locked districts in Timor Leste and the centre of the country's coffee harvesting territory. Rafael lives with his wife in a traditional Timorese house in, and is a farmer by trade. Looming over the village is Mount Ramelau, providing shade from the scorching sun and humidity - a welcome relief for the local villagers. Rafael has three sons - one who works with the United Nations as an interpreter in the capital, the other two support their father on the farm. The family grows tropical fruits, particularly bananas, mangoes and mangosteens.

Ermera is three hours away from the national hospital in Dili. The trek from this rural region to central Dili is arduous. The dirt roads are steep, serpentine and stomach churning. Despite these challenging conditions, Rafael De Jesus and his son Juan Guan Gonzalez have made the journey to Dili, as Rafael is now legally blind. Rafael has bilateral senile cataracts. Over the past year there has been a painless, gradual reduction in vision in his right eye. During the last five months visual deterioration has also progressed in his left eye resulting in legal blindness in both eyes. Rafael can only see light in his right eye and has some vision in his left. To put this in context, the definition of legal blindness is a visual acuity of 6/60 or worse with both eyes open.

Three months prior to this visit to Dili, an Outreach team from the National Eye Centre travelled to Ermera and gave Rafael the opportunity to be operated upon for cataracts. Cataracts are the most common cause of visual decline in Timor. During this visit he was offered surgery but declined as his son Juan, who is stationed in Dili, preferred to look after his father in the post-operative period - and thus would not give immediate consent. Family consent is an integral part of Timorese culture. If the family does not agree with the operation, then it may not go ahead irrespective of the patient's wishes. Local and expatriate staff from the National Eye Centre must work within this context.

Another three months passed until Rafael's surgery was rescheduled, this time in Dili. Rafael was one of ten others lined up in the corridors of the National Eye Centre, donned with a green disposable cap and gown awaiting surgery. We had the opportunity to interview him (along with a translator) prior to the surgery. Rafael was extremely happy to be undergoing sight restoring cataract surgery as over the past year, along with the decline of his sight there has been a large loss of independence. Psychologically, the inability to work on the farm was the hardest part of losing his sight.



Left: Rafael De Jesus and son, Juan Guan Gonzalez. Right: Rafael De Jesus awaiting surgery at the National Eye Centre in Dili, Timor Leste.

## Surgery and Sequelae

The skill and efficiency of the ophthalmologists at the National Eye Centre is exemplified in cases such as this one. It is the norm for technically difficult cataracts like these to be removed with minimal complications. Resembling free-flowing water which turns white, mature cataracts adopt a similar opaque appearance. They cloud the patient's vision and are challenging to remove.

Rafael's surgery was successful. On the first day after the operation, follow-up revealed immediate improvement in vision to his right eye. Previously Rafael could only respond to light, but now he had 6/12 vision. Put simply, at 6 meters he could see what a patient with no visual difficulties could see at 12 meters. A tremendous improvement!

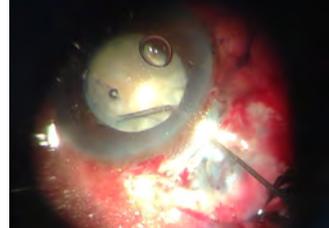
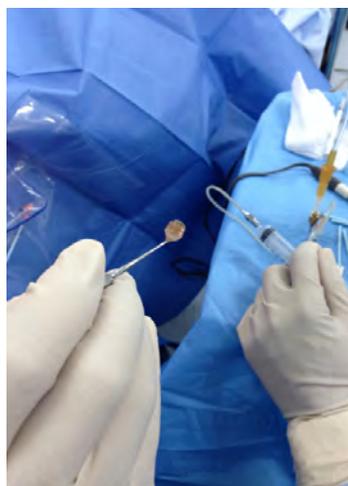
Given the success of his right cataract surgery, plans are now in motion to also correct the vision in Rafael's left eye.

## Linguistic Challenges

Communication and language barriers are perhaps the most difficult hurdles to overcome in the setting of the National Eye Centre. With the exception of Dr. Marcelino Correia, the first Timorese ophthalmologist, all the ophthalmologists are expatriates. Tetun, English, Bahasa Indonesia, Chinese and Spanish are all spoken at the Centre. This can present challenges in communication. Additionally, the number of Tetun dialects from the different districts is also significant when interacting with patients. The cultural pot pourri and mix of languages makes for a linguistically diverse environment.



Image: Rafael and Juan on day one post right eye small incision cataract surgery (SICS)



Top: Intraoperative photograph of cataract surgery in progress with a hydro-dissection cannula in view, used in order to eject the nucleus from the lens into the anterior chamber. Below Left: Rafael is prepared for right cataract extraction & IOL instertion. Below Right: Illustration of three way irrigating vectus balancing the opacified intra-ocular lens.

## The consequences of remoteness

Similar to health care in Australia, one of the major problems in Timor Leste is bringing health services to the rural population. Twenty-five per cent of households are more than two hours from their closest health-care centre. This is not only due to the long distances from facilities like the National Eye Centre but also due to poor infrastructure including roads and transport difficulties<sup>1</sup>.

From these poor living conditions and logistical challenges stem tragic cases as that of seven year old Sayema. Sayema lives with her family 3-4 hours away from Dili. Screened by the outreach team due to a 2-month

history of 'itchy, uncomfortable eye', she was referred for further care at the National Eye Centre. Another two months passed before her parents were able to bring her into Dili to see the ophthalmologists. Upon examination, a diagnosis of severe, refractory uveitis was made.

Four months after the initial presentation it was now 'burnt-out' - and the visual acuity was only light perception. The outcomes for Sayema are tragic. She will be permanently blind in her left eye. The underlying cause of the uveitis is still unknown, however may be linked to numerous systemic diseases such as juvenile arthritis and tuberculosis or an unnoticed traumatic event. The main goal of care now is to maintain sight in her remaining eye. She will need regular follow-ups at the National Eye Centre.

## National Eye Centre – Restoring the 'sight' of a Nation

Events like this could be avoided with improved patient education and awareness, enabling early presentation and therefore intervention. All these issues stem from barriers that will take time and widespread transformations to overcome. For now, the doctors and eye care workers do their best to work within the current system. The National Eye Centre marks a positive step toward restoring the vision of the people and the 'sight' of a Nation.

### References

1. Deen J, Matos C, Temble B, da Silva J, Liberato S, da Silva V, Soares AL, Joshi V, Moon S, Tulloch J, Martins J, Mullholland K. Identifying national health research priorities in Timor-Leste through a scoping review of existing health data. Health Research Policy and Systems 2013; 11(1).

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Consent was obtained by all individuals involved in this case for the publication of any photographs and of information divulged.

