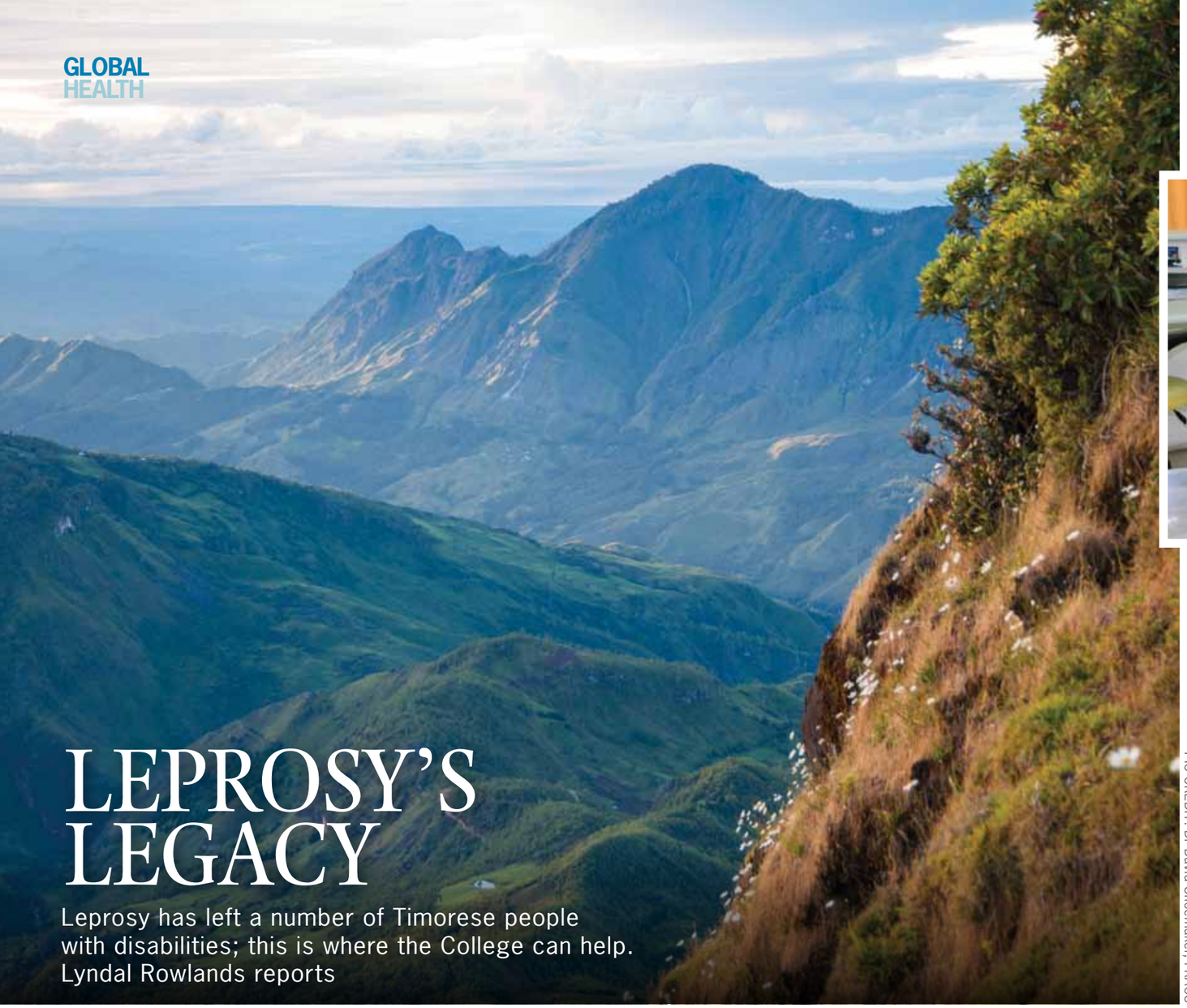

LEPROSY'S LEGACY

Leprosy has left a number of Timorese people with disabilities; this is where the College can help. Lyndal Rowlands reports

PIC CREDIT: Dr David Shoemaker, FRACS

Joel shows the improved movement in his hands to Julie Hamilton

Joel's story

By the end of 2013, some of the muscles in Joel da Costa's left forearm had pulled his fingers back so far that he could no longer straighten them, leaving his hand in a 'claw'-like shape. Growing up in Timor-Leste during years of civil unrest and poverty, Joel missed out on early intervention for his leprosy. Although he started treatment in 2007, it was only enough to slow his symptoms progressing, not to stop them entirely.

By 2010, the nerves in Joel's hands had become affected. A course of steroid treatment helped, but did not restore nerve function and by 2013, Joel was experiencing weakness, muscle imbalance and a loss of sensation in his hands, as well as the 'claw'-ing of his left hand.

This is when Dr David Hamilton, FRACS and his physiotherapist wife Julie Hamilton, who have worked in Timor-Leste for 10 years, recommended that Joel would be a good candidate for tendon transfer surgery.

Describing the surgery, Joel says, "First Dr David told me that the operation would move the tendon of one of my muscles. When I heard that I was afraid, but now that I have more use of my hand, it is ok."

Joel began to feel more confident about having the operation when he remembered that he had seen two other leprosy patients doing post-operative exercises, and that their hands were no longer clawed.

For Joel, the operation will make a big difference to his everyday life, especially his work as a disability support worker. Joel lives and works in the mountainous district of Aileu. Although Aileu is less than 50 kilometres from the national capital Dili, the mountains rise steeply along the short journey reaching almost 3000 feet. The roads are some of the worst in Timor-Leste and difficult to negotiate at the best of times. It is these roads that Joel needs to navigate on his motorbike every day to get to work and see his clients. Joel received an assistance device in 2010 to help support his hand, but found the device made it more difficult to ride his motorbike. As he began to lose the grip in his left hand, Joel found it increasingly difficult to navigate the roads safely and he ended up coming off his motorbike.

Although Joel was taking his medication and doing hand strengthening exercises, it became clear that surgery was needed to help his hand to recover.

Leprosy in Timor-Leste

The World Health Organisation has had an active leprosy elimination program in Timor-Leste since 2003, providing free multi-drug therapy to help stop the disease from progressing. However, leprosy remains a serious health problem in some parts of Timor-Leste, including in the coastal enclave of Oecusse, which the World Health Organization says is thought to have been a leprosy colony during Portugal's colonisation of Timor-Leste.

The World Health Organization explains that for Timor-Leste, "because of the often long incubation period of leprosy, there remains a significant backlog of hidden cases in the community that have still to be diagnosed, because they are not yet showing any clinical signs of the disease."

Early treatment with multi-drug therapy and, if necessary, steroids, can stop the physical symptoms of leprosy from progressing, however due to the instability of Timor-Leste during years of occupation and unrest, many patients, including Joel, were not able to access this treatment straight away.

David and Julie Hamilton

Dr David Hamilton, FRACS, and his physiotherapist wife Julie Hamilton have had a long term commitment to working in both Papua New Guinea and Timor-Leste. Their work has covered many areas, including the treatment of leprosy.

Julie first became interested in treating leprosy as a physiotherapy student in Dunedin, New Zealand, over 50 years ago; she completed training in India before going to work at the Leprosy Reconstructive Surgical Unit in Madang, Papua New Guinea. Julie introduced David to her interest in leprosy and the two have since spent decades working and volunteering in Papua New Guinea and Timor-Leste. ▶

"In Papua New Guinea when I was based in Madang in the mid-60s, our unit treated 400 hands in two years. Prevalence should be reducing now that they have triple drug therapy."

David explains, "I learned how to do the tendon transfers from Ken Clezy. I did three or four of the tendon operations a year in the '70s and '80s while working in Papua New Guinea.

"Tendon transfer surgery is becoming increasingly rare. It was originally developed to treat polio patients, and with the near eradication of polio in most countries, and effective multi-drug therapy to treat leprosy, there are now fewer surgeons doing this operation."

David and Julie have been coming to Timor-Leste since 2005, with 2014 being their 10th visit.

On their most recent visit, David was invited by the College to teach general surgical Trainees at the national hospital in Dili. His teaching appointment was through the Australian Government funded Australia Timor-Leste Program of Assistance in Secondary Services – Phase II (ATLASS II), a program managed by the College. It employs five specialist doctors as teachers at the national hospital in Surgery, Emergency Medicine, Obstetrics/Gynaecology, Paediatrics and Anaesthesia.

During this visit, David completed four tendon transfer operations. Two surgical Trainees, from the national hospital assisted. "Dr Raimundo scrubbed and did parts of the operations and Dr Gustodio also assisted," David said.

Dr Raimundo is a graduate of the first Post Graduate Diploma in Surgery to be delivered in Timor-Leste while Dr Gustodio is completing the first year of his Master's in Medicine at the University of Papua New Guinea. Neither of these doctors would have been able to complete their training in surgery in their home country without College support.

Joel's Recovery

Joel rests his elbow on the table while Julie applies individual plasters to each of his fingers. She explains that for the first week of post-operative physiotherapy, the plaster cylinders will be changed every second day and for the next two to three weeks they will be removed and reapplied daily to allow for flexion exercises to be practiced.

Joel first met Julie when he was still in high school.

"I contacted the Leprosy Mission to assist with some teaching, and they told me they also had a patient who wanted to see me," Julie said.

Sara, a Timorese physiotherapist, keenly observes and assists Julie as she goes through the rehabilitation exercises with Joel. Julie and Sara have improvised to make equipment to help Joel strengthen his hands, including using a plastic water bottle which Joel grasps and lifts to strengthen his grip.

Julie has been showing Sara how to teach the leprosy patients to use their transferred muscles, and how to apply the plaster cylinders.

Just a few weeks after his operation, Joel is already seeing improvement in his hand. Unlike before his surgery, he now has a good functional grip and his fingers are no longer clawed. He still isn't quite ready to use the motorbike for his hand needs to become stronger, but with further strengthening exercises he should be able to get back to work soon.

CASE NOTE REVIEW

GUY MADDERN
CHAIR, ANZASM

Rupture after endoluminal graft for aortic aneurysm does occur

An elderly patient awoke with abdominal pain. As the pain persisted the patient called an ambulance just after lunchtime, when the patient was transported to the Emergency Department (ED). The patient was assessed by the Triage personnel soon after arriving at the ED, but was not seen by a doctor for more than five hours after calling the ambulance. At that time the patient's history consisted of constant left iliac fossa pain, leg pain, nausea and loose bowel action. Routine blood tests were ordered and an Intravenous (IV) cannula inserted. A surgical referral was made.

The patient was assessed by the surgical registrar. A similar presenting history was obtained, but in addition a past history of a left femoropopliteal bypass and an endoluminal repair of an abdominal aortic aneurysm performed five years prior were obtained. The Blood Pressure (BP) was 100/70. An abdominal Computed Tomography (CT) scan was ordered and performed just after midnight. Shortly afterwards, the radiologist reporting the CT rang the ED doctor to report a ruptured left iliac aneurysm with massive retroperitoneal haemorrhage. The surgical registrar contacted the vascular surgical registrar.

At just before midnight on the day of admission, the patient's BP was recorded as 120/95. The next recorded BP measurement was taken just before the CT scan and measured <80 mmHg. At 1.40 am, the BP was unrecordable. A dose of 500 ml of Gelofusine was administered and this was followed by a further 500 ml at 2.20 am. At 2.25 am, the patient was transferred to the operating theatre. This was more than 13 hours after the patient had sought emergency assistance and 12 hours after arriving in the ED.

On arrival in the operating theatre, the patient was unresponsive, bradycardic with agonal breathing. A decision was made that surgical intervention would be futile, and the patient died.

Reviewer's comments

The case notes are scant, but adequate. However:

This was an avoidable death. Had treatment been undertaken during the period of haemodynamic stability, the patient would likely have survived. The decision not to proceed with the operation when the patient was moribund is not questioned. The delays in the management of this patient presenting to the ED compounded the lack of experience and knowledge of the assessing clinical staff.

There is a lack of understanding apparent in this ED with respect to a patient with an endoluminal aortic repair that is probably common to most EDs. Endoluminal abdominal aortic aneurysm repairs do not cure the aneurysm, they merely control it. Thus a patient with unexplained abdominal and/or back pain should be assumed to have a complication of the endoluminal repair until proven otherwise.

There were unacceptable delays in the management of this patient at every stage – inappropriate triage delayed medical review for hours, the CT scan was not for almost 10 hours and even when the diagnosis was known, transfer to the operating theatre was delayed for more than one hour. These delays directly contributed to the death of the patient. It would be reassuring to know that the institution involved has conducted an internal review of this patient's poor management.

It would be reasonable to consider promulgating the concept that endoluminal repair of an abdominal aortic aneurysm does not cure the aneurysm and that rupture can still occur. Any patient with a history of an endoluminal repair of an abdominal aortic aneurysm who presents with unexplained abdominal or back pain should be considered to possibly have a complication of their endoluminal repair and urgent abdominal CT scan should be arranged.