Annual Report

2022

EAST TIMOR HEARTS FUND

Australians supporting a healthy Timor-Leste

Benvindu | Welcome

Our mission:

La'o Hamutuk – Walking together for heart health.

We will collaborate with people, government and health institutions in Timor-Leste to support development of local capacity and improve access to cardiac care and heart disease prevention in Timor-Leste.

Acknowledgement of Traditional Owners

We acknowledge the Traditional Owners of the land, the Wurundjeri people of the Kulin Nation. We recognise their continuing connection to land, waters and culture. We pay our respects to their Elders past, present and emerging. We commit ourselves and our organisation to helping Timor-Leste to reduce the country's very high rates of cardiovascular disease and in particular rheumatic heart disease.

Thank you for your generous continued support.

East Timor Hearts Fund's work is only possible due to the generosity of our amazing community of supporters, volunteers and partners. We sincerely thank you for your contribution and support.

Contents

4 Our Board

5 Chair's Report

6 CEO's Report

7 2022 Highlights

10 Program Impact - Education & Prevention

12 Program Impact - Diagnosis & Treatment

16 Investing in greater impact

18 Financial statements

Our Board

East Timor Hearts Fund is guided by a dedicated Board of Directors who volunteer their time. The Board is responsible for the overall governance, management and strategic direction of the organisation and for delivering accountable corporate performance in accordance with the organisation's goals and objectives.

David Lloyd
Board Chair

Vijaya Joshi
Board Director &
Deputy Chair

Prof. Peter Barlis
Board Director &
Chair of Clinical
Governance Committee

Prof. Sandra Eades AO
Board Director

Belinda Macdonald
Board Director &
Chair of Development
Committee

David Mayne
Board Director

Alzira dos Reis
Board Director &
Chair of the Timorese
Advisory Committee

Katrina Thurston
Board Director &
Chair of Finance and
Audit Committee

Peter Walton
Board Director

Dr Will Wilson
Board Director

Chair's Report

East Timor Hearts Fund has an incredible history of supporting Timorese people affected by rheumatic heart disease and congenital heart disease by delivering cardiac screening clinics in Timor-Leste and bringing patients to Australia for life-saving heart surgery. Since starting in 2010, we have saved the lives of more than 100 patients through heart surgery.

2022 was a year of evolution as we strengthened our foundations for greater impact. In the last few years we have collaborated with Timorese and international health organisations on innovative projects such as developing and implementing the Timor-Leste RHD Guidelines. The Guidelines provide evidence-based guidance for clinicians for the diagnosis, treatment and prevention of acute rheumatic fever and rheumatic heart disease. Such initiatives have been truly embraced and championed by the Timor-Leste Ministry of Health and local health organisations as a real game changer for the healthcare system and community. It is a game changer because of the potential positive flow on impact. By equipping Timorese clinicians with the skills and capacity to reduce the burden of rheumatic heart disease, they become the change agents to reach more patients now and in future.

Through such initiatives the Board saw an opportunity to build on our legacy while strengthening programs that build local capacity to prevent and treat rheumatic heart disease. In line with the Board's strategic plan.

The first of these investments was to increase our operational skills. The Board was delighted to appoint Jane Papasergio as our new CEO in February. We also welcomed a new board member, Peter Walton who is the CEO of CARE Australia. Jane and Peter bring an incredible depth of experience in international development in Asia and the Pacific.

Training clinicians and improving health care systems within a developing country takes time. While we started investing in 2022, the momentum of our change impact will likely be realised in later years as we continue to look for ways to achieve the greatest impact. It is, therefore, important for us to stay focused and continue to pursue opportunities to walk together with the Timorese people to build their capacity to affect real, sustainable change.

David Lloyd
Chair, East Timor Hearts Fund

> This year has been one of evolution as we strengthen our foundations for greater impact in the next decade.

CEO's Report

After a couple of challenging years with COVID-19 border restrictions in both Australia and Timor-Leste, it was wonderful to be able to start our cardiac screening clinics in Timor-Leste again in April, and bringing patients to Australia for heart surgery in May.

When I first joined East Timor Hearts Fund in February 2022 I had heard of the amazing work of our volunteer clinicians and partners in Timor-Leste. It was incredible to witness this first hand when I joined a cardiac screening clinic in Dili. It was also heartwarming and inspiring to welcome our patients to Australia, and see how surgical intervention transformed not only their lives, but those of their families and loved ones too.

I continue to be inspired by our life-changing work and the opportunities for even greater impact. Projects such as our early prevention penicillin programs provide monthly penicillin to 426 patients to prevent their rheumatic heart disease from getting worse. Or how we are supporting the socialisation of the Timor-Leste RHD Guidelines so that clinicians can be trained to identify, prevent and treat acute rheumatic fever and rheumatic heart disease.

I'm looking forward to ETHF developing further partnerships and supporting the expansion of programs to allow a greater impact on prevention and capacity building. This will enable us to help achieve our mission of reducing the burden of rheumatic heart disease.

Due to more than two years of COVID-19 restrictions, we had a backlog of patients needing surgery. We addressed this by bringing 10 patients to Australia to receive life-saving surgery, which resulted in an increase in our operating costs.

While COVID eased in 2022, the softening economy and increase in cost of living created new challenges and negatively impacted our fundraising. We've also brought more patients to Australia amidst this. I have been especially heartened by the continued support of our generous donors. Thank you to everyone who supported our organisation. Without you, our life-changing work would not be possible.

I would also like to thank the Board, Finance and Clinical Governance Committees for their leadership and dedication to our organisation. And lastly our small core team for their hard work and support.

Jane Papasergio
CEO, East Timor Hearts Fund

> I continue to be inspired by our life-changing work and the opportunities for even greater impact.

2022 Highlights

April

The first in-country cardiac clinic in two years was held after COVID restrictions eased.

May

After two years of COVID restrictions, six patients came to Australia for life-saving heart surgery.

April

Socialisation of the RHD Guidelines started. We worked with local healthcare partners to train health professionals on diagnosing and treating rheumatic heart disease.

July

Supporters do Run Melbourne to raise funds for East Timor Hearts Fund.

August

Supporters attended our first in person event post COVID - the screening of the documentary Take Heart, Deadly Heart.

Nov

Our co-founder Dr Noel Bayley, was awarded the prestigious Medal of the Order of Timor-Leste by the Government of Timor-Leste.

Program Impact - Education & Prevention

To have the most effective reach and impact, we partner with local healthcare organisations to deliver Rheumatic Heart Disease programs in a broad range of health settings including hospitals, Community Health Services, Health Centres, and SISCa centres (integrated health service program in the community).

Education and awareness programs

ETHF supports the delivery of a range of education and awareness programs for health workers, family members and the community about the dangers of rheumatic heart disease and how they can detect and prevent it.

A key education program is the socialisation of the Timor-Leste RHD Guidelines and RHD Patient Held Medical Records (PHMR-RHD) which were developed in 2021 by healthcare partners including ETHF, the Timor-Leste Ministry of Health, Maluk Timor, Menzies Health Research and St John of God (SJoG).

The RHD Guidelines and related training modules provide evidence-based guidance for clinicians for the recognition, diagnosis, treatment and prevention of acute rheumatic fever and RHD. By training clinicians our aim is to help them identify patients with ARF and RHD early, so patients receive treatment early and improve their health outcomes.

The PHMR-RHD enables healthcare workers to document patients' medical visits. Patients can carry it with them to every medical appointment. This promotes consistent record keeping of patient visits for better continuity and quality of care. It also encourages greater patient responsibility and autonomy in their healthcare journey.

In 2022, we continued to support the socialisation and training of the RHD Guidelines and PMHR-RHD in five districts: in Aileu, Baucau, Bobonaro, Dili and Ermera.

Early prevention program

Our early prevention program provides patients with monthly penicillin injections or oral doses over several years to prevent their disease from getting worse. Without access to the penicillin program, patients' rheumatic heart disease will deteriorate. They may develop other health complications and eventually will need heart surgery. However, heart surgery is significantly more costly and is a more invasive procedure than the penicillin program. Also, heart surgery isn't currently available in Timor-Leste and patients must travel overseas to countries such as Australia for surgery.

For the penicillin treatment to be most effective, patients should receive penicillin as early as possible after diagnosis, and consistently keep up with their monthly doses.

Some patients struggle to travel to a clinic regularly because they live in a rural or remote area. Others may need encouragement to continue their course of medication. To increase the likelihood of patients continuing with the program, penicillin clinics are delivered in a range of locations. Home visits are also conducted to engage hard to reach patients and healthcare staff provide support and information to patients and their family.

Program Impact - Diagnosis & Treatment

Cardiac screening clinics

During 2022, East Timor Hearts Fund held three cardiac screening clinics: in April, July/August, and October at HNGV and HOREX Baucau. Our team of volunteer Australian clinicians partnered with Maluk Timor, HNGV and HOREX Baucau to conduct 262 patient consultations, of which 85 were male and 177 were female.

During the clinics, the team reviewed current RHD patients as well as assessed newly referred patients. We consulted with patients on their medications, penicillin, doses, family planning options. We also identified patients who needed cardiac surgery and recommended the type of surgery they would need.

Initiation of primary care for patients who were too fearful to get vaccinated against COVID was an important benefit for patients attending the clinics. A very common theme encountered during the clinics was that of patients not being vaccinated against COVID due to concerns regarding vaccines causing heart damage.

Reassurance was provided to patients that they would be much safer with some protection against COVID. The Maluk Timor team have also been comprehensively liaising with all patients to ensure they are protected.

During the clinic, our team used the RHD medical record book to document the patient's healthcare visits. Patients can take the record book with them to every health facility to keep an accurate record of important information for continuity of care. The clinical team also used the RHD Guidelines, developed in collaboration with the Ministry of Health and HNGV to ensure treatment complied with the national treatment requirements.

Patients who live in rural and remote areas and could not afford to travel to a clinic were offered a small travel allowance to enable them to attend.

By the end of clinic held in October, there were 34 patients on our waitlist requiring cardiac surgery.

Cardiac screening clinics delivered in 2022

Clinic date	Location	Number patient consultations	Number of male patient consultations	Number of female patient consultations
Friday 1 April to Monday 4 April 2022	HNGV, Dili	81	26	55
Friday 29 July to Monday 1 August	HNGV, Dili	61	18	43
Friday 14 October to Saturday 15 October	HNGV, Dili	96	33	63
Sunday 16 October	HOREX, Baucau	24	8	16
Number of patient consultations		**262**	**85**	**177**

> East Timor Hearts Fund provides an important service for a very prevalent disease that can be prevented and/or treated. If not, it can lead to devastating consequences.
>
> Brandon Lau
> July 2022 clinics

4

Clinics held

262

Patient consultations

Thank you to the clinicians from Australia who volunteered in our cardiac clinics in 2022:

April clinics

- Dr Alan Appelbe
- Dr Annette Appelbe
- Dr Noel Bayley
- Julie Kean

July clinics

- Dr Virag Kushwaha
- Dr Joan Li
- Dr Andrew Mamo
- Brandon Lau (medical student)

October clinics

- Dr Simon Eggleton
- Dr Elizabeth Paratz
- Dr Tracey Breen
- Rebecca Paratz (medical student)

Thank you also to the clinicians at our partner organisations including:

- From Maluk Timor - Dra Joaquina Maurays, Mana Juliana Sarmento, Maun Anary dos Santos and Maun Sergio da Silva.
- From HNGV - Dr Saturnino de Jesus, Dr Andre Monteiro, Dr Herculano dos Santos, Dr Domingos da Costa, Dr Cesaltino Leao, Dr Alito Soares, Dr Marcelino Correia, and Dr Waldo Paula.

Cardiac surgeries

During 2022, East Timor Hearts Fund provided life-saving heart surgery in Australia for 10 adult Timorese patients. Eight of the patients were female and two were male. Six patients underwent Percutaneous Mitral Balloon Valvuloplasty procedures and four patients underwent open heart surgery. All patients returned to Timor-Leste with good outcomes following their surgery.

The surgeries were conducted by Australian cardiologists who have volunteered with East Timor Hearts for several years. East Timor Hearts Fund partnered with Maluk Timor to brief patients and manage their travel to and from Australia.

The patients were accompanied by a Timorese Patient Escort from either Maluk Timor or East Timor Hearts Fund. The Patient Escort provided guidance and support for patients as well as acted as translators to patients and clinical teams in Australia.

By the end of December 2022, we will have 28 patients on our waitlist requiring cardiac surgery.

Cardiac surgeries performed in 2022

Month of surgery	Location	Type of surgery	Number patients	Number of male patients	Number of female patients
May	Eastern Heart Clinic	Percutaneous Mitral Balloon Valvuloplasty	4	0	4
May	St John of God Geelong	Open heart	2	0	2
November	St John of God Geelong	Open heart	2	2	0
December	Eastern Heart Clinic	Percutaneous Mitral Balloon Valvuloplasty	2	0	2
Number of patients			**10**	**2**	**8**

Cardiac surgeries by patient age and surgery performed

Patient age	Patient gender	Heart condition	Type of surgery
19	Female	Atrial septum defect	Open heart - repair atrial septum defect
19	Female	Rheumatic mitral stenosis	Percutaneous Mitral Balloon Valvuloplasty
23	Male	Rheumatic mitral valve disease	Open heart - mitral valve replacement
24	Female	Rheumatic mitral stenosis	Percutaneous Mitral Balloon Valvuloplasty
30	Female	Rheumatic mitral stenosis	Percutaneous Mitral Balloon Valvuloplasty
33	Male	Rheumatic mitral valve disease	Open heart - mitral valve replacement
34	Female	Rheumatic mitral stenosis	Percutaneous Mitral Balloon Valvuloplasty
35	Female	Rheumatic mitral valve disease	Open heart - mitral valve replacement
40	Female	Rheumatic mitral stenosis	Percutaneous Mitral Balloon Valvuloplasty
40	Female	Rheumatic mitral stenosis	Percutaneous Mitral Balloon Valvuloplasty

> Thank you to all the donors and doctors. Your support, kindness and sincerity in helping people like me couldn't be expressed in words.

Ricardo
November 2022

Ricardo

Ricardo is a thirty three year old father with three children. He has been living with rheumatic heart disease since he was 14 years old. Our cardiologists diagnosed him with critical aortic valve stenosis. His heart disease prevented him from doing many things. "It really affected by dreams because whatever activities I did would be limited."

Ricardo had been on our surgery list, for a few years due to COVID travel restrictions. In late November he travelled to Australia for open heart surgery and is now recovering well.

Maria

Maria is a mother to five young kids including six-week-old twin boys. Since childhood she suffered from severe rheumatic heart valve disease. At seven months into her pregnancy Maria developed heart failure putting her life and both of her unborn twins at risk.

In late May Maria received life-saving heart surgery at St John of God Hospital Geelong. She's now enjoying doing the simple things we take for granted – like playing with her children.

Investing in greater impact

This year, the East Timor Hearts Fund Board approved a three year strategic plan (from 2022 to 2024) to have greater impact by reducing the number of people in Timor-Leste affected by acute rheumatic fever and rheumatic heart disease. The four goals that underpin the plan are:

1. Help grow the capacity of health providers in Timor-Leste to deliver quality heart healthcare.
2. Support assessment clinics and life-saving heart surgery whilst building heart disease prevention and education programs.
3. Partner with leading local organisations to reduce the burden of heart disease in Timor-Leste.
4. Strengthen our organisation and grow our community of supporters including multilateral funders (e.g. the United Nations), bilateral funders (e.g. Australian Government), corporates, trusts and foundations.

In 2022, we started investing in the resources and expertise necessary to lay the foundations for greater future impact and bring the plan to life.

Since ETHF started, we have had a small core operations team has been based in Australia. Two years ago, we hired our first employee based in Timor-Leste. Then in September 2022 we welcomed our second employee in Timor-Leste. In future, we aim to continue increasing our operational presence in Timor-Leste to grow our programs and impact. This may include establishing an ETHF office in Timor-Leste and/or strengthening collaboration with local healthcare partners.

Our strategic plan is informed by The [Timor-Leste] National Health Sector Strategic Plan 2011-2030 which emphasises the need for an ongoing focus on improving health systems management and developing skills in health professionals. Therefore, to best support Timorese people to reduce the burden of rheumatic heart disease, our plan prioritises capacity building of local healthcare professionals, with an emphasis on delivering heart disease prevention and education programs.

The ETHF team has been collaborating with our local partner Maluk Timor to explore expanding existing programs such as socialisation of the RHD Guidelines and the penicillin early prevention program.

We have also been consulting with the Ministry of Health and local healthcare organisations to develop programs targeted at different groups of patients and clinicians. For example, ways to support women and children who are at greater risk of developing RHD. Or tailored training modules for Timorese cardiologists.

Developing and delivering new healthcare programs will involve intensive time and resource commitment to navigate systems and build relationships of mutual trust in the early years. It also involves trialing ideas, learning from and strengthening them. This means that the impact of our investment in 2022 to 2024 is expected to be greater in future years.

Financial Statements

Summarised Statement of Profit & Loss and Other Comprehensive Income

For the year ended 31 December 2022

Income	2022 $	2021 $
Charitable Support - Bequests	69,881	–
Charitable Support – Non-Bequests	230,481	329,865
Interest and investment Income	117,517	120,210
COVID-19 Income	–	18,000
Gain on sale of investments	–	7,070
Membership Fees Income	1,545	1,500
Total	**419,424**	**476,645**

Expenditure		
Patient support expenses	(254,112)	(178,392)
Loss on sale of investments	(95,292)	–
Fundraising expense	(40,615)	(35,190)
Employee benefit expenses	(371,005)	(294,563)
Depreciation expense	(3,066)	(4,979)
Administration expense	(80,710)	(34,482)
Total expenses	**(844,800)**	**(547,606)**
Deficit/Surplus for the year	(425,376)	(70,961)
Other comprehensive income	(188,575)	208,080
Total comprehensive income for the year	**(613,951)**	**137,119**

Summarised Statement of Financial Position

For the year ended 31 December 2022

Current Assets	2022 $	2021 $
Cash and cash equivalents	102,381	172,214
Receivables	52,530	69,728
Prepayments	8,889	16,898
Investments	2,469,143	2,997,746
Total current assets	2,632,943	3,256,586
Non-current Assets		
Property, plant and equipment	5,477	7,469
Total non-current assets	5,477	7,469
Total assets	**2,638,420**	**3,264,055**
Current Liabilities		
Payables	53,797	62,532
Employee entitlements	16,506	19,455
Total current liabilities	70,303	81,987
Total Liabilities	**70,303**	**81,987**
Net assets	**2,568,117**	**3,182,068**
Equity		
Retained earnings	2,435,811	2,861,187
Revaluation Reserve	132,306	320,881
Total equity	**2,568,117**	**3,182,068**

Thank you to our volunteers

Thank you to all our incredible volunteers who have helped East Timor Hearts Fund to save lives in 2022.

Board Directors

- Professor Peter Barlis
- Mana Alzira dos Reis
- Professor Sandra Eades AO
- Belinda Hillard
- Vijaya Joshi
- David Lloyd
- David Mayne
- Katrina Thurston
- Peter Walton
- Dr Will Wilson

Timorese Advisory Committee

- Dr Domingos da Costa
- Dr Rui Maria de Araujo
- Mana Regina de Sousa
- Mana Alzira dos Reis
- Dr Frederico Bosco Alves dos Santos
- Mana Macu Guterres
- Dra Joaquina Maurays
- Dr Marcelino Vincente Correia

Clinical Governance Committee

- Dr Alan Appelbe
- Dr Noel Bayley
- Professor Andrew Cochrane
- Dr Louise Creati
- Dr Simon Eggleton
- Dr Sarah Gutman
- Dr Ari Horton
- Dr Virag Kushwaha
- Dr Elizabeth Paratz
- Professor Jaishankar Raman

Operations and Administration

- James Dickie - Company Secretary
- David Gerrard - Finance and Audit Committee member
- Nicki Mock - Clinical administration
- Jacqueline Tan - Finance administration

Patient Support

- Olga Gago
- Catherine Mahar
- Ana Saldanha

Cardiac Surgeons

- Associate Professor Cheng-Hon Yap
- Dr Virag Kushwaha

“On behalf of my parents and all my family, thank you very much for your big help to support my operation in Australia.

Joana
May 2022

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EAST TIMOR HEARTS FUND
Australians supporting a healthy Timor-Leste