

THIRD  
REPORT OF THE  
NATIONAL TRANSPLANT REGISTRY  
2006

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## FOREWORD

The development of organ and tissue transplantation in this country continues to make progress although at a pace many wish could be faster. Many factors continue to challenge the development of organ transplantation. The high cost of doing organ transplantation has been cited as a frequent impediment to doing more transplantation. Yet there has never been a case where organ transplantation in this country has been deferred or put off because the patient cannot afford it. We are fortunate in that the government has been supportive and subsidized heavily the cost of doing transplantation. Almost all solid organ transplantation is done in public hospitals either in the Ministry of Health or Ministry of Higher Education. There have been numerous campaigns in both the print and electronic media to create greater public awareness and although there is a surge of interest after each dramatic report of a donation by a cadaver donor, we are not seeing that many more donation as expected. The organ procurement team will no doubt continue with its efforts to promote cadaveric organ donation. Another factor that has been addressed recently is the organizational and support structure to facilitate transplantation. The Ministry of Health has now reorganized the structure of the transplantation service, developed a national policy on organ and tissue transplantation and allocated substantial funds for human resource development and improvement of facilities. These measures hopefully will bear fruit in the near future.

In recent years much attention were directed to the unsavory aspect of kidney transplantation – the commercial cadaveric transplantation in China and the live donor kidney transplantation in Pakistan and Philippines in particular. Authorities in these countries have now banned such transplantation. The number of kidney transplantations done in China has dropped dramatically and the overall figures for kidney transplantation reported to the National Transplant Registry (NTR) in 2007 was the lowest in many years. Many countries in the world have resorted to increasing the live related donor pool to overcome the shortage of kidneys. In some the number of live related kidney transplantation has overtaken that of cadaveric kidney transplantation. It is time that this country redirects its efforts to improve the live related kidney transplantation program. Many end stage renal failure (ESRF) patients have not been properly counseled on the benefits of transplantation but are often shunted straight to dialysis.

This report continues to document the progress made in organ and tissue transplantation in the country. We are grateful to the centres, the doctors and their staff who have painstakingly collected data and submitted them to NTR. We hoped the data in this registry will be of use to them and can assist them in planning future development, audit activities and stimulate research.

Tan Sri Dato Dr Yahya Awang  
Chairperson

Dato Dr Zaki Morad  
Co-chairperson

Datin Dr Lela Yasmin Mansor  
Co-chairperson

NATIONAL TRANSPLANT REGISTRY

## ACKNOWLEDGEMENTS

The National Transplant Registry would like to record its appreciation to everyone who have helped made this report possible.

We would especially like to thank the following:

- Our source data providers that are the transplant surgeons, physicians and staff of all organ and tissue transplant centres and transplant follow up centres from the government, universities and private sectors, without whose commitment, hard work and timely data submission, there will be no report
- National Renal Registry for sharing the renal transplant data
- Clinical Research Centre, Hospital Kuala Lumpur
- Ministry of Health, Malaysia
- The members of the various expert panels for their expertise and for devoting their valuable time and effort in preparing and writing the various chapters
- And not forgetting our following supporters from the industry and other well-wishers:

Roche (M) Sdn. Bhd.  
Norvartis Corporation (M) Sdn. Bhd.  
Janssen-Cilag Div., Johnson & Johnson Sdn. Bhd.  
GlaxoSmithKline Pharmaceutical Sdn. Bhd.

## **PARTICIPATING CENTRES**

### **Discipline: Blood and Marrow Transplant**

1. Ampang Puteri Specialist Hospital
2. Division of Haematology, Department of Medicine, University of Malaya Medical Centre
3. Haematology Department, Hospital Ampang
4. Haematology Department, Hospital Kuala Lumpur
5. Haematology Department, Subang Jaya Medical Centre
6. Maybank BMT Centre, Hospital Universiti Kebangsaan Malaysia
7. Oncology-Haematology Department, Gleneagles Medical Centre, Penang
8. Oncology-Haematology Department, Lam Wah Ee Hospital
9. Paediatric BMT Unit, Department of Paediatrics, University of Malaya Medical Centre
10. Paediatric BMT Unit, Institute of Paediatrics, Hospital Kuala Lumpur
11. Paediatric BMT Unit, Subang Jaya Medical Centre

### **Discipline: Bone and Tissue Transplant**

1. Bone Bank, Hospital Kuala Lumpur
2. Bone Bank, University of Malaya Medical Centre
3. Department of Orthopaedic & Traumatology, Hospital Kangar
4. Department of Orthopaedic Surgery, Hospital Alor Setar
5. Department of Orthopaedic Surgery, Hospital Taiping
6. Department of Orthopaedic Surgery, University of Malaya Medical Centre
7. Department of Orthopaedics, Hospital Ipoh
8. Department of Orthopaedics, Hospital Kajang
9. Department of Orthopaedics, Hospital Kota Bharu
10. Department of Orthopaedics, Hospital Kuala Terengganu
11. Department of Orthopaedics, Hospital Kuantan
12. Department of Orthopaedics, Hospital Pulau Pinang
13. Department of Orthopaedics, Hospital Seberang Jaya
14. Department of Orthopaedics, Hospital Sultanah Aminah
15. Department of Orthopaedics, Hospital Tengku Ampuan Rahimah
16. Department of Orthopaedics, Hospital Universiti Sains Malaysia
17. Department of Orthopaedics, Sarawak General Hospital
18. Department of Orthopaedics, Sultanah Fatimah Specialist Hospital
19. Department of Orthopaedics, Traumatology and Rehabilitation, International Islamic University Malaysia
20. Department of Surgery, Hospital Kota Bharu
21. Hospital Fatimah, Ipoh
22. Institute of Orthopaedic & Traumatology, Hospital Kuala Lumpur
23. Island Hospital, Penang
24. Kota Bharu Medical Centre
25. Malaysian Institute For Nuclear Technology Research
26. National Tissue Bank, Universiti Sains Malaysia
27. Normah Medical Specialist Centre, Kuching
28. Ophthalmology Department, Hospital Alor Setar
29. Ophthalmology Department, Hospital Kuala Lumpur
30. Ophthalmology Department, Hospital Sungai Buloh

**Discipline: Bone and Tissue Transplant**

31. Ophthalmology Department, Hospital Teluk Intan
32. Ophthalmology Department, Hospital Tengku Ampuan Afzan
33. Ophthalmology Department, Hospital Tengku Ampuan Rahimah
34. Ophthalmology Department, Hospital Universiti Sains Malaysia
35. Ophthalmology Department, Sri Kota Medical Centre
36. Timberland Medical Centre, Kuching
37. Wan Orthopaedic, Trauma & Sports Injury Centre, Seremban Specialist Hospital

**Discipline: Cornea Transplant**

1. Eye Clinic, Mahkota Medical Centre
2. Hope Eye Centre, Gleneagles Intan Medical Centre, Kuala Lumpur
3. K.C. Yeo Eye Specialist Centre
4. Ophthalmology Department, 94 Hospital Angkatan Tentera Kem Terendak
5. Ophthalmology Department, Gleneagles Medical Centre, Penang
6. Ophthalmology Department, Hospital Alor Setar
7. Ophthalmology Department, Hospital Batu Pahat
8. Ophthalmology Department, Hospital Bukit Mertajam
9. Ophthalmology Department, Hospital Duchess of Kent, Sandakan
10. Ophthalmology Department, Hospital Ipoh
11. Ophthalmology Department, Hospital Kangar
12. Ophthalmology Department, Hospital Kota Bharu
13. Ophthalmology Department, Hospital Kuala Lipis
14. Ophthalmology Department, Hospital Kuala Lumpur
15. Ophthalmology Department, Hospital Kuala Pilah
16. Ophthalmology Department, Hospital Kuala Terengganu
17. Ophthalmology Department, Hospital Melaka
18. Ophthalmology Department, Hospital Mentakab
19. Ophthalmology Department, Hospital Miri
20. Ophthalmology Department, Hospital Pakar Sultanah Fatimah
21. Ophthalmology Department, Hospital Pantai Indah
22. Ophthalmology Department, Hospital Pulau Pinang
23. Ophthalmology Department, Hospital Putrajaya
24. Ophthalmology Department, Hospital Queen Elizabeth, Kota Kinabalu
25. Ophthalmology Department, Hospital Selayang
26. Ophthalmology Department, Hospital Seremban
27. Ophthalmology Department, Hospital Sibu
28. Ophthalmology Department, Hospital Sultan Ismail
29. Ophthalmology Department, Hospital Sultanah Aminah
30. Ophthalmology Department, Hospital Sungai Buloh
31. Ophthalmology Department, Hospital Sungai Petani
32. Ophthalmology Department, Hospital Taiping
33. Ophthalmology Department, Hospital Tawau
34. Ophthalmology Department, Hospital Teluk Intan
35. Ophthalmology Department, Hospital Tengku Ampuan Afzan
36. Ophthalmology Department, Hospital Tengku Ampuan Rahimah
37. Ophthalmology Department, Hospital Umum Sarawak
38. Ophthalmology Department, Hospital Universiti Kebangsaan Malaysia

**Discipline: Cornea Transplant**

39. Ophthalmology Department, Hospital Universiti Sains Malaysia
40. Ophthalmology Department, Sri Kota Medical Centre
41. Ophthalmology Department, University of Malaya Medical Centre
42. Pusat Pakar Mata Centre For Sight, PJ
43. Puteri Specialist Hospital, Johor Bahru
44. Sunway Medical Centre
45. Tan Eye Specialist Centre, Sunway Medical Centre
46. Tun Hussein Onn National Eye Hospital

**Discipline: Heart and Lung Transplant**

1. Cardiothoracic Department, Institut Jantung Negara
2. Institut Perubatan Respiratori, Hospital Kuala Lumpur

**Discipline: Heart Valve Transplant**

1. Cardiovascular Tissue Bank, Department of Cardiothoracic Surgery, Institut Jantung Negara

**Discipline: Liver Transplant**

1. Department of Paediatrics, University of Malaya Medical Centre
2. Hepatobiliary Department, Hospital Selayang
3. Paediatric Hepatology Unit, Hospital Selayang
4. Institute of Paediatrics, Hospital Kuala Lumpur
5. Subang Jaya Medical Centre

**Discipline: Renal Transplant**

1. 96 Hospital Angkatan Tentera Kem Lumut
2. C. S. Loo Kidney & Medical Specialist Centre
3. Nephrology Department, Hospital Alor Setar
4. Nephrology Department, Hospital Batu Pahat
5. Nephrology Department, Hospital Bintulu
6. Nephrology Department, Hospital Duchess of Kent
7. Nephrology Department, Hospital Ipoh
8. Nephrology Department, Hospital Kangar
9. Nephrology Department, Hospital Kemaman
10. Nephrology Department, Hospital Kluang
11. Nephrology Department, Hospital Kuala Lumpur
12. Nephrology Department, Hospital Kuala Terengganu
13. Nephrology Department, Hospital Labuan
14. Nephrology Department, Hospital Melaka
15. Nephrology Department, Hospital Miri
16. Nephrology Department, Hospital Pakar Sultanah Fatimah
17. Nephrology Department, Hospital Pontian
18. Nephrology Department, Hospital Pulau Pinang
19. Nephrology Department, Hospital Queen Elizabeth

**Discipline: Renal Transplant**

20. Nephrology Department, Hospital Raja Perempuan Zainab II
21. Nephrology Department, Hospital Segamat
22. Nephrology Department, Hospital Selayang
23. Nephrology Department, Hospital Serdang
24. Nephrology Department, Hospital Seremban
25. Nephrology Department, Hospital Sibul
26. Nephrology Department, Hospital Sultan Ismail Pandan
27. Nephrology Department, Hospital Sultanah Aminah
28. Nephrology Department, Hospital Taiping
29. Nephrology Department, Hospital Tawau
30. Nephrology Department, Hospital Tengku Ampuan Afzan
31. Nephrology Department, Hospital Tengku Ampuan Rahimah
32. Nephrology Department, Sarawak General Hospital
33. Nephrology Department, UKM Hospital
34. Nephrology Department, University Malaya Medical Centre
35. Nephrology Department, USM Hospital
36. Nephrology Unit, Ampang Puteri Specialist Hospital
37. Nephrology Unit, Mahkota Medical Centre
38. Nephrology Unit, Subang Jaya Medical Centre
39. Nephrology Unit, Sunway Medical Centre
40. Paediatric Renal Transplant Clinic, Hospital Kuala Lumpur
41. Paediatric Ward, Hospital Sultanah Aminah
42. Renal Dialysis Centre Sdn. Bhd.
43. Renal Transplant Clinic, Sabah Medical Centre
44. Renal Transplant Clinic, Selangor Medical Centre
45. Renal Transplant Clinic, Sri Kota Medical Centre
46. Renal Transplant Unit, Hospital Pantai Mutiara
47. S.P. Menon Dialysis Centre, Klang
48. Simon Wong Medical & Kidney Clinic, Timberland Medical Centre
49. Smartcare Dialysis Centre, Cheras
50. Smartcare Dialysis Centre, Subang Jaya
51. Tan Medical Renal Clinic



## **ABOUT THE NATIONAL TRANSPLANT REGISTRY**

The National Transplant Registry (NTR) is a Ministry of Health (MOH) supported registry whose aim is to collect information about organ and tissue transplantations in Malaysia. The information allows us to estimate the magnitude of transplant activity in the country. Such information besides being useful to transplantation practitioners, can be used in assisting the MOH, non-governmental organisations, private providers and industry in program planning and evaluation of transplantation services.

The objectives of NTR are to:

1. Determine the frequency and distribution of all types of transplantation activity in Malaysia.
2. Determine the outcomes of transplantation.
3. Determine the factors influencing outcomes of transplantation.
4. Evaluate transplantation services in the country.
5. Stimulate and facilitate research on transplantation and its management.

The NTR receives data on organ / tissue transplantation from 3 main sources:

1. The individual doctors who provide transplantation services, who voluntarily report data to the NTR. Data collection will be from seven main types of transplantation services:
  - Blood and Marrow Transplant
  - Cornea Transplant
  - Heart and Lung Transplant
  - Liver Transplant
  - Renal Transplant
  - Heart Valve Transplant
  - Bone and Tissue Transplant
2. The National Vital Registration system (Jabatan Pendaftaran Negara). Their data is useful for determining or verifying mortality outcomes of transplant patients.
3. Information Documentation Unit of the MOH, which operates the Health Management Information System (HMIS).

## **NTR SPONSORS**

- Medical Development Division, MOH
- National Transplant Coordinating Committee
- Malaysian Society Of Transplantation
- Clinical Research Centre, Hospital Kuala Lumpur

## GOVERNANCE BOARD

The Governance Board is established by NTR sponsors to govern the NTR. Current members of the Governance Board are as follows:

<b>Name</b>	<b>Representation</b>
Tan Sri Dato' Dr Yahya Awang <b>Chairperson</b>	Cardiothoracic Consultant, Damansara Specialist Hospital NTR Expert Panel Chairman of Heart / Lung Transplant
Dato' Dr Zaki Morad Mohd Zaher <b>Co-chair</b>	Head, Department of Nephrology, Hospital Kuala Lumpur NTR Expert Panel Chairman of Renal Transplant
Datin Dr Fadhilah Zowiyah Lela Yasmin Mansor <b>Co-chair</b>	Chairperson, Registry Subcommittee National Transplant Coordinating Committee Ministry Of Health
Dr Teng Seng Chong	Medical Development Division, Ministry of Health
Dr Tan Chwee Choon	Malaysian Society of Transplantation
Dr Lim Teck Onn	Clinical Research Centre (CRC), Hospital Kuala Lumpur
Dr Jamaiah Haniff	Clinical Research Centre (CRC), Hospital Kuala Lumpur
Mr Rohan Malek	Malaysian Urological Association
Dr Hooi Lai Seong	Malaysian Society of Nephrology
Dr Aizai Azan Abdul Rahim	National Heart Association of Malaysia
Dr Suzina Sheikh Ab. Hamid	Malaysian National Tissue Bank
Dr Wong Jun Shyan	Ophthalmological Society Of MMA
Tan Sri Datuk Dr Mohd. Ismail Merican	Malaysian Liver Foundation
Dr Hamidah Shaban	Malaysian Thoracic Society
Dr Wan Faisham	Malaysian Orthopaedic Association
Dr Gill Satwant Singh	National Kidney Foundation of Malaysia
Dr Chang Kian Meng	Malaysian Society of Haematology
Dr Kelvin Lim Lye Hock	Malaysian Association of Oral & Maxillofacial Surgeons
Dr R T Arasu	Malaysian Dental Association
Dr Alan Teh Kee Hean	NTR Expert Panel Co-chair of Blood and Marrow Transplant (Adult)
Prof Dr Chan Lee Lee	NTR Expert Panel Co-chair of Blood and Marrow Transplant (Paediatric)
Dato' Dr Zakaria Zahari	NTR Expert Panel Chairman of Liver Transplant
Dr Shamala Retnasabapathy	NTR Expert Panel Chairperson of Cornea Transplant
Dr Goh Bak Leong	NTR Expert Panel Co-chair of Renal Transplant
Mr Mohamed Ezani Hj Md. Taib	NTR Expert Panel Co-chair of Heart / Lung / Heart Valve Transplant
Prof Zulmi Wan	NTR Expert Panel Chairman of Bone and Tissue Transplant

## EXPERT PANEL

NTR has established seven groups of Expert Panel comprising members of the medical profession and allied health with expert knowledge in these various disciplines:

- Blood and Marrow Transplant
- Cornea Transplant
- Heart and Lung Transplant
- Liver Transplant
- Renal Transplant
- Heart Valve Transplant
- Bone and Tissue Transplant

The role of the Expert Panel is:

1. To undertake quality control of the clinical registry form and the data dictionary.
2. To undertake quality control of the reported data.
3. To undertake literature review in the relevant area.
4. To interpret the results generated by NTR's statisticians.
5. To write the section of the NTR report relevant to the panel expertise.
6. To specify the data reporting procedure.
7. To facilitate access to source documents for Transplant Registry Unit (TRU) staff to do data verification.

List of Expert Panel members for each respective discipline:

### **Discipline: Blood and Marrow Transplant**

<b>Co-chair (Adult)</b>	Dr Alan Teh Kee Hean
<b>Co-chair (Paeds)</b>	Prof Dr Chan Lee Lee
<b>Members</b>	Prof Dr Cheong Soon Keng
	Dr Chang Kian Meng
	Dr Gan Gin Gin @ Gan Shiao Sze
	Dr Hishamshah Mohd Ibrahim
	Dr Jameela Sathar
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	Dr Mahfuzah Mohamed
	Dr Ng Soo Chin
	Dr S Visalachy Purushothaman
	Dr Vijaya Sangkar

### **Discipline: Cornea Transplant**

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<b>Co-chair</b>	Dr Choong Yean Yaw
<b>Members</b>	Dato' Dr Veera Ramani
	Dr Jonathan Choon Siew Cheong
	Dr Chuah Kay Leong
	Dr Michael Law Sie Haur

	Dr Mariam Ismail
	Assoc Prof Dr SC Reddy
	Dr Sahimi Sulaiman
	Dr U Thiageswari

**Discipline: Heart and Lung Transplant**

<b>Chairman</b>	Tan Sri Dato' Dr Yahya Awang
<b>Co-chair</b>	Mr Mohamed Ezani Hj Md. Taib
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	Dr Ashari Yunus
	Dr Aizai Azan Abdul Rahim
	Dato' Dr David Chew Soon Ping
	Dr Hamidah Shaban

**Discipline: Liver Transplant**

<b>Chairman</b>	Dato' Dr Zakaria Zahari
<b>Members</b>	Dr Ganesalingam A/L Kanagasabai
	Dr Goon Hong Kooi
	Dr Lim Chooi Bee
	Prof Dr Lee Way Seah
	Dr Sushila Sivasubramaniam
	Dr Tan Soek Siam
	Dr S Thavaranjitham

**Discipline: Renal Transplant**

<b>Chairman</b>	Dato' Dr Zaki Morad Mohd Zaher
<b>Co-chair</b>	Dr Goh Bak Leong
<b>Members</b>	Dr Fan Kin Sing
	Dr Lily Mushahar
	Mr Rohan Malek
	Dr S Prasad Menon
	Prof Dr Tan Si Yen

**Discipline: Heart Valve Transplant**

<b>Chairman</b>	Mr Mohamed Ezani Hj Md.Taib
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**Discipline: Bone and Tissue Transplant**

<b>Chairman</b>	Prof Dr Zulmi Wan
<b>Members</b>	Dr Suzina Sheikh Ab Hamid
	Dr Badrul Shah Badaruddin
	Dato' Dr Hasim Mohamad
	Dr Norimah Yusof
	Dr Robert Penafort

## **NTR STAFF**

Clinical Registry Coordinator                      Ms Leong Wei Chee

## **SUPPORTING STAFF FROM THE CLINICAL RESEARCH CENTRE**

The Clinical Research Centre (CRC) of the Ministry of Health provides technical support for the National Transplant Registry. The clinical epidemiologists provide methodological and epidemiological input while the database is supported on CRC's IT infrastructure.

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Information & Communication Technology (ICT) Manager	Ms Celine Tsai Pao Chien
Network Administrator	Mr Kevin Ng Hong Heng
Assistant Network Administrator	Mr Adlan Ab. Rahman
Database Administrator	Ms Lim Jie Ying
Desktop publisher	Ms Azizah Alimat

## **BIOSTATISTICAL CONSULTANTS**

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Consultant Biostatistician	Dr Hoo Ling Ping
Biostatistician	Mr Tan Wei Hao
Biostatistician	Ms Lena Yeap Lay Ling

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