

NINTH
REPORT OF THE
NATIONAL TRANSPLANT REGISTRY
2012

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November 2015

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Published by:

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Suggested citation of this report is as follows:

Hooi LS, Lela Yasmin Mansor (Eds). Ninth Report of the National Transplant Registry Malaysia 2012. Kuala Lumpur 2015.

The electronic version of this report can be downloaded at:

<http://www.mst.org.my/ntrSite>

Disclaimer

There is a potential that data for previous years printed in this report are different from what were printed in previous reports. This is because analysis for this report is based on the latest dataset in the web which may have been updated by SDP.

Foreword

The Council of the Malaysian Society of Transplantation is pleased to present the 9th National Transplant Registry Report which summarises the cumulative data related to organ donation & transplantation activities in Malaysia up to, and including, 31st December 2012.

The primary role of the National Transplant Registry is to document, analyse and assess organ donation and transplantation activities in Malaysia. The data generated from each organ donation and transplant procedure is collected, collated, analysed and included in the Registry. This data has been the basis for the various interventions and planning initiatives undertaken over the years to develop transplantation in this country. This registry has fostered a culture of transparency, accountability and sharing of information to further enhance and improve transplantation services in Malaysia.

The Malaysian Society of Transplantation wishes to acknowledge the crucial and extremely vital role played by the editors, Dr Hooi Lai Seong & Datin (Dr) Fadhilah Zowyah Lela Yasmin Mansor, the members of the steering committee, the experts' panel, the source data providers and the Registry Manager, Mr Naren Kumar Surendra for their enormous effort in the preparation of this report.

The National Transplant Registry would not be sustainable if not for the continued support and commitment of all transplant professionals, the Ministry of Health Malaysia and our corporate sponsors. We wish to record our immense gratitude to each and every individual who has contributed in one way or other towards the preparation and eventual successful release of this report. We hope that you will find this edition of the National Transplant Registry Report for 2012 to be both useful and informative.

We, at the Malaysian Society of Transplantation are committed to maintain the National Transplant Registry ad infinitum and work closely with all stakeholders to develop and enhance organ donations and transplantation in our country.

Datuk (Mr) Harjit Singh MBBS; FRCSEd; FRCSI
President, Malaysian Society of Transplantation

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:

- Director General of Health, Malaysia
- Ministry of Health, Malaysia
- 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
- National Clinical Research Centre, Ministry of Health
- Health Informatics Centre, Ministry of Health
- 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
- Roche (M) Sdn. Bhd, and Astellas Malaysia for their support in providing sponsorships
- Encik Adam bin Bujang, Head of Biostatistics Unit, National Clinical Research Centre for the audit of statistical analysis of this report.
- Many others, whose names are not listed here, for their support.

PARTICIPATING CENTRES

Discipline: Blood and Marrow Transplant

1. Haematology Department, Hospital Pulau Pinang
2. Division of Haematology, Department of Medicine, University of Malaya Medical Centre
3. Haematology Department, Hospital Ampang
4. Haematology Department, Sime Darby Medical Centre Subang Jaya
5. Haemopoietic Stem Cell Transplant Unit, Hospital Universiti Sains Malaysia
6. Maybank BMT Centre, Universiti Kebangsaan Malaysia Medical Centre
7. Paediatric BMT Unit, Department of Paediatrics, University of Malaya Medical Centre
8. Paediatric BMT Unit, Institute of Paediatrics, Hospital Kuala Lumpur
9. Paediatric BMT Unit, Sime Darby Medical Centre Subang Jaya
10. Gleneagles Medical Centre, Penang

Discipline: Bone and Tissue Transplant

1. Bone Bank, Hospital Kuala Lumpur
2. Bone Bank, University of Malaya Medical Centre
3. National Tissue Bank, Universiti Sains Malaysia

Discipline: Cornea Transplant

1. Ophthalmology Department, Hospital Kuala Lumpur
2. Ophthalmology Department, Hospital Melaka
3. Ophthalmology Department, Hospital Sungai Buloh
4. Gleneagles Medical Centre, Penang
5. Ophthalmology Department, Hospital Umum Sarawak
6. Ophthalmology, Hospital Sultan Ismail
7. Pusat Pakar Mata Centre For Sight, Petaling Jaya
8. Tun Hussein Onn National Eye Hospital
9. Ophthalmology Department, University Malaya Medical Centre
10. Ophthalmology, Sri Kota Medical Centre
11. Ophthalmology Department, Hospital Sultanah Bahiyah

Discipline: Heart and Lung Transplant

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

Discipline: Heart Valve Transplant

1. Cardiothoracic Department, Institut Jantung Negara
2. Cardiovascular Tissue Bank, Institute Jantung Negara

Discipline: Liver Transplant

1. Hepatobiliary Department, Hospital Selayang
2. Paediatric Hepatology Unit, Hospital Selayang

Discipline: Renal Transplant

1. Nephrology Clinic (Renal Transplant), Hospital Kuala Lumpur
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3. Renal Transplant Clinic, Hospital Bintulu
4. Renal Transplant Clinic, Hospital Duchess of Kent
5. Renal Transplant Clinic, Hospital Kemaman
6. Renal Transplant Clinic, Hospital Enche' Besar Hajjah Khalsom
7. Renal Transplant Clinic, Hospital Labuan
8. Renal Transplant Clinic, Hospital Melaka
9. Renal Transplant Clinic, Hospital Mersing
10. Renal Transplant Clinic, Hospital Miri
11. Renal Transplant Clinic, Hospital Pakar Sultanah Fatimah
12. Renal Transplant Clinic, Hospital Pontian
13. Renal Transplant Clinic, Hospital Raja Permaisuri Bainun
14. Renal Transplant Clinic, Hospital Sultanah Aminah
15. Renal Transplant Clinic, Hospital Sultanah Bahiyah
16. Renal Transplant Clinic, Hospital Queen Elizabeth
17. Renal Transplant Clinic, Hospital Segamat
18. Renal Transplant Clinic, Hospital Selayang
19. Renal Transplant Clinic, Hospital Serdang
20. Renal Transplant Clinic, Hospital Taiping
21. Renal Transplant Clinic, Hospital Tawau
22. Renal Transplant Clinic, Hospital Tengku Ampuan Afzan
23. Renal Transplant Clinic, Hospital Tengku Ampuan Rahimah
24. Renal Transplant Clinic, Hospital Tuanku Ja'afar
25. Renal Transplant Clinic, Hospital Sibul
26. Renal Transplant Clinic, Hospital Sultanah Nur Zahirah
27. Renal Transplant Clinic, Hospital Raja Perempuan Zainab II
28. Renal Transplant Clinic, Hospital Sultanah Nora Ismail
29. Nephrology Clinic (Renal Transplant), Hospital Sultan Ismail (Paed)
30. Renal Transplant Clinic, Hospital Sultan Ismail
31. Renal Transplant Clinic, Hospital Dungun
32. Renal Transplant Clinic, Sarawak General Hospital
33. Renal Transplant Clinic, Hospital Pulau Pinang
34. Renal Transplant Clinic, Universiti Kebangsaan Malaysia Hospital
35. Renal Transplant Clinic, Universiti Sains Malaysia Hospital
36. Renal Transplant Clinic, Universiti Malaya Medical Centre
37. Renal Transplant Clinic, KPJ Ampang Puteri Specialist Hospital
38. Renal Transplant Clinic, Prince Court Medical Centre
39. Klinik Dr Choo & Liew
40. Renal Transplant Clinic, Sabah Medical Centre
41. Tan Medical Renal Clinic
42. Fan Medical Renal Clinic Sdn Bhd
43. Kidney Unit, Assunta Hospital
44. Renal Transplant Clinic, Timberland Medical Centre,
45. Renal Transplant Clinic, Renal Care, Ipoh Specialist Hospital

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

**MALAYSIAN SOCIETY OF TRANSPLANTATION COUNCIL MEMBERS
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Dr. Shamala Retnasabapathy

Dato' Dr. Sharifah Suraya bt. Syed Mohd. Tahir

NTR STEERING COMMITTEE

The Steering Committee is established to govern the NTR and the terms of reference are as follows:

1. Provide professional and expert input on subject matters to the National Transplant Registry.
2. Monitor the performance and progress of National Transplant Registry to ensure its continued relevance.
3. Review and implement recommendations of the Governance Board.
4. Assist in enlisting source data providers for the National Transplant Registry and facilitate access to source data.
5. Motivate Source Data Providers to continue participating in the activities of the National Transplant Registry.
6. Disseminate information about the National Transplant Registry.
7. Communicate the National Transplant Registry report data / information locally and internationally.
8. Approve, and if necessary validate, the statistical analysis plan for the National Transplant Registry.
9. Review and approve applications for the use of registry data.

Chairperson

Dr Hooi Lai Seong
Hospital Sultanah Aminah

Vice Chairperson

Datin Dr Fadhilah Zowyah Lela Yasmin Mansor
National Transplant Resource Centre

Members:

Dato' Dr.Chang Kian Ming	Hospital Amapng
Dr Chandramalar T. Santhirathelagan	Hospital Sungai Buloh
Dr Ganesalingam A/L Kanagasabai	Sime Darby Medical Centre
Assoc. Prof. Dr Suzina Sheikh Ab. Hamid	Hospital University Sains Malaysia
Dr Chan Lee Lee	Sime Darby Medical Centre
Prof Dato' Mr. Mohd Ezani Hj Md. Taib	National Heart Association of Malaysia
Dr Goh Pik Pin	National Clinical Research Centre

Clinical Registry Manager

Naren Kumar A/L Surendra

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 as deemed necessary.
2. To undertake quality control of the reported data.
3. To undertake literature review on 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's 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

Co-chairperson (Adult)	Dato Dr.Chang Kian Ming
Co-chairperson (Paeds)	Dr Hishamshah Mohd Ibrahim
Members	Prof Gan Gin Gin @ Gan Shiaw Sze
	Dr Chan Lee Lee
	Prof Madya Dr S Fadilah Abdul Wahid
	Dr Ong Tee Chuan
	Dr Alan Teh Kee Hean

Discipline: Cornea Transplant

Chairperson	Dr Shamala Retnasabapathy
Members	Prof Dato' Dr Veera Ramani
	Dr Choong Yean Yaw
	Dr Thiageswari Umopathy
	Dr Chandramalar Santhirathelagan

Discipline: Heart and Lung Transplant

Chairperson	Mr Mohamed Ezani Hj Md. Taib
Members	Dato' Dr David Chew Soon Ping
	Dr Aizai Azan Abdul Rahim
	Dr Abdul Rais Sanusi
	Dr Ashari Yunus

Discipline: Liver Transplant

Chairperson	Dr Ganesalingam A/L Kanagasabai
Members	Dr Lim Kin Foong
	Dr Haniza Omar
	Dr Lim Chooi Bee
	Prof Dr Lee Way Seah

Discipline: Renal Transplant

Chairperson	Dr Goh Bak Leong
Members	Dato' Dr (Mr) Rohan Malek
	Dr. Woong Hin Seng
	Dr S Prasad Menon
	Dr. Rosnawati Yahya
	Dr. Fan Kin Sing

Discipline: Bone and Tissue Transplant

Chairperson	Dr Suzina Sheikh Ab Hamid
Members	Assoc Prof Dr Azura Mansor
	Assoc Prof Dr Ahmad Hafiz Zulkifly
	Dr Thiageswari Umapathy
	Dr Ewe Teong Wan
	Dr Norimah Yusof
	Assoc Prof Dr Vivek Ajit Singh

Discipline: Deceased (Cadaveric) Organ and Tissue Donations

Chairperson	Datin Dr Fadhilah Zowyah Lela Yasmin Mansor
Members	Dr Hooi Lai Seong
	Dr Omar Sulaiman
	Dr Muhammed Anis Bin Abdul Wahab
	Matron Jamaliah Kario
	Staff Nurse Santi A/P Krishanan
	Dr. Rosnawati Yahya
	Dr Hani Nadhirah Zakaria

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