

Title:

**Section 1.0 NZBMDR STANDARDS  
INTRODUCTION**

Authorised by:

Executive Officer

Contributing Authors:

ABMDR

Dr Hilary Blacklock

Raewyn Fisher

## **Table of Contents**

**SECTION 1.0 NZBMDR STANDARDS  
INTRODUCTION**

1.1	Foreword.....	3
1.2	National management Committee.....	4
1.3	Scientific Expert Advisory Committee.....	5
1.4	Ethics Committee.....	6
1.5	Medical Review Panel.....	6
2.0	NZBMDR Relationships.....	7
3.0	Consultants and Advisors to NZBMDR .....	8

## SECTION 1.0 NZBMDR STANDARDS INTRODUCTION

### 1.1 FOREWORD

Transplantation of haemopoietic stem cells is currently the only curative therapy for a number of diseases of the bone marrow including severe aplastic anaemia and some forms of leukaemia

Approximately 30% of patients suitable for transplantation are fortunate enough to have a fully matched sibling or other family member who can act as a bone marrow donor. The remaining **70% of patients do not have a suitable related donor**. Donors have to be very well matched for the Human Leucocyte Antigens (HLA), since even relatively minor mismatches lead either to rejection of the transplant or to graft-versus-host disease.

The first case of transplantation of bone marrow from an unrelated but matched donor was in 1973, and **the first successful unrelated transplant was performed in 1979 in Seattle**. In 1987 results of the first major series of unrelated transplants became available from which it was clear that unrelated donors who were matched with the recipients for HLA, could lead to successful transplants and a cure for chronic myeloid leukaemia (CML).

In 1996 the New Zealand Bone Marrow Donor registry was formally established. The Blood Transfusion Trust was authorized by the Minister of Health (under a formal contract for services) to establish the terms and conditions for the operation of a New Zealand Bone Marrow Donor Registry (NZBMDR).

In 1997 the Blood Transfusion Trust entered into an agency agreement with the Leukaemia and Blood Foundation (LBF) which authorised the LBF to operate the NZBMDR. The Blood Transfusion Trust was replaced by the New Zealand Blood Service (NZBS) in 1998, with the same responsibilities to the NZBMDR.

In 2008 NZBS and LBF signed a Letter Of Understanding re the operations of the NZBMDR by the Leukaemia and Blood Foundation

Bi-Annual reports are to be provided by the NZBMDR National Management Committee, to the Ministry of Health via Auckland District Health Board (ADHB), the Leukaemia and Blood Foundation (LBF) and the NZ Blood Service (NZBS)

The NZBMDR consists of a national register of donors and is the link between the clinical transplant units and the New Zealand Blood Service (NZBS). Testing is conducted in the NZBS Blood Processing, Accreditation, Reference and Tissue Typing Laboratories.

The NZBMDR national office, based in the New Zealand Blood Service, Auckland, has computer links worldwide with other registries and with Bone Marrow Donors Worldwide (BMDW).

# New Zealand Bone Marrow Donor Registry

---

NZBMDR was accredited by the (WMDA) World Marrow Donor Association in May 2006.

In December 2008 an Occupation Licence was signed between NZBS and NZBMDR formalising the exiting arrangements for occupation of an office within the NZBS complex

The office physical address is  
71 Great South Rd  
Epsom, AUCKLAND 1051

The postal address is  
P O Box 74336  
Market Rd  
Auckland 1543

NZBMDR Office hours are 8.30 to 5.00 Monday to Friday .

Telephone: + 64 9 5235756

Fax: +64 9 5235757

Mobile available 24 hours 0274 588661

[nzbmdr@nzblood.co.nz](mailto:nzbmdr@nzblood.co.nz)

The Leukaemia and Blood Foundation of NZ (LBF) is responsible for administering the NZBMDR and managing the financial aspects.

A formal link exists between the LBF on behalf of the NZBMDR and the Australian Bone Marrow Donor Registry (ABMDR) who provide access to NZBMDR to list their donors on the ABMDR database .

The Ministry of Health (MOH) is responsible for national policy and funding. A contract for provision of service exists between the LBF and the Ministry of Health

## **1.2. NATIONAL MANAGEMENT COMMITTEE**

### **1.2.1 AIM**

The aim of the National Management Committee (NMC) is to provide management and coordination of a national service and to oversee the provision of suitably matched, unrelated voluntary donors of haemopoietic stem cells for patients in need of such transplantation.

### **1.2.2 Terms of Reference**

- (i) National coordination of the NZBMDR and responsibility for the maintenance, storage and processing of the national stem cell database.
- (ii) Determine appropriate guidelines for:

- a) recruitment, registration and recall of potential donors
  - b) acceptance of both search requests and subsequent transplantation, to and from New Zealand and International Registries
- (iii) Pursue international collaboration for the benefit of New Zealand patients, with countries who have established registries and for those countries wishing to establish registries
- (iv) Report activity regularly to the Ministry of Health and other relevant agencies

### 1.2.3 Membership

Medical Director (Chairman)	Dr Hilary Blacklock
NZBS Donor Centre Representative	Dr Sushanta Ghosh
Medical Director of NZ Blood Service	Dr Peter Flanagan
NZBMTSC (New Zealand Bone Marrow Transplant Study Group) representative	Current Chair
APHIA (Asia, Pacific, Histocompatibility and Immunogenetics Association) representative	Dr Paul Dunn
Pediatric Haematology representative	Dr Lochie Teague
Maori representative	Mr Rea Wikaira / Craig Harris
LBF (Leukaemia and Blood Foundation) Executive Director	Ms Pru Etcheverry
National NZBMDR Executive Officer	Ms Raewyn Fisher

## 1.3 SCIENTIFIC EXPERT ADVISORY COMMITTEE (SCEAC)

### 1.3.1 Terms of Reference

To advise the National Management Committee on:

- All aspects of tissue typing technology.

- All aspects of stem cells transplantation technology.
- All aspects of donor - recipient matching.
- The scientific merit of research proposals involving the NZBMDR as outlined in Section 16.0 - Scientific Research and Publications.

## 1.3.2 Membership

Medical Director	Dr Hilary Blacklock.
ASEATTA representative	Dr Paul Dunn
NZBMTSG chairperson	Current Chair
Paediatric Haematology representative	Dr Lochie Teague

## 1.4 ETHICS COMMITTEE

### 1.4.1 Ethical Appraisal of Activity

The NZBMDR uses the Auckland Ethical committee to apply for ethical approval of the introduction of new treatments. This is particularly important with respect to activities relating to voluntary donors, and issues related to Maori and Pacific Islanders.

Any institution planning research, which utilises material collected by the NZBMDR, would need to seek approval from the National Management and Scientific committees, before applying to their relevant ethics committee.

## 1.6 MEDICAL REVIEW PANEL

### 1.5.1

#### Terms of Reference

To advise the National Management Committee on:

- Level of HLA Matching

- Collection (including third party haematological assessment, the donation process, subsequent and repeat donations, non standard , high risk or experimental HPC donation or other related procedures)
- Post donation care and follow up.

### **1.5.2 Membership**

Medical Director

NZBMTSG chairperson

NZBS representative

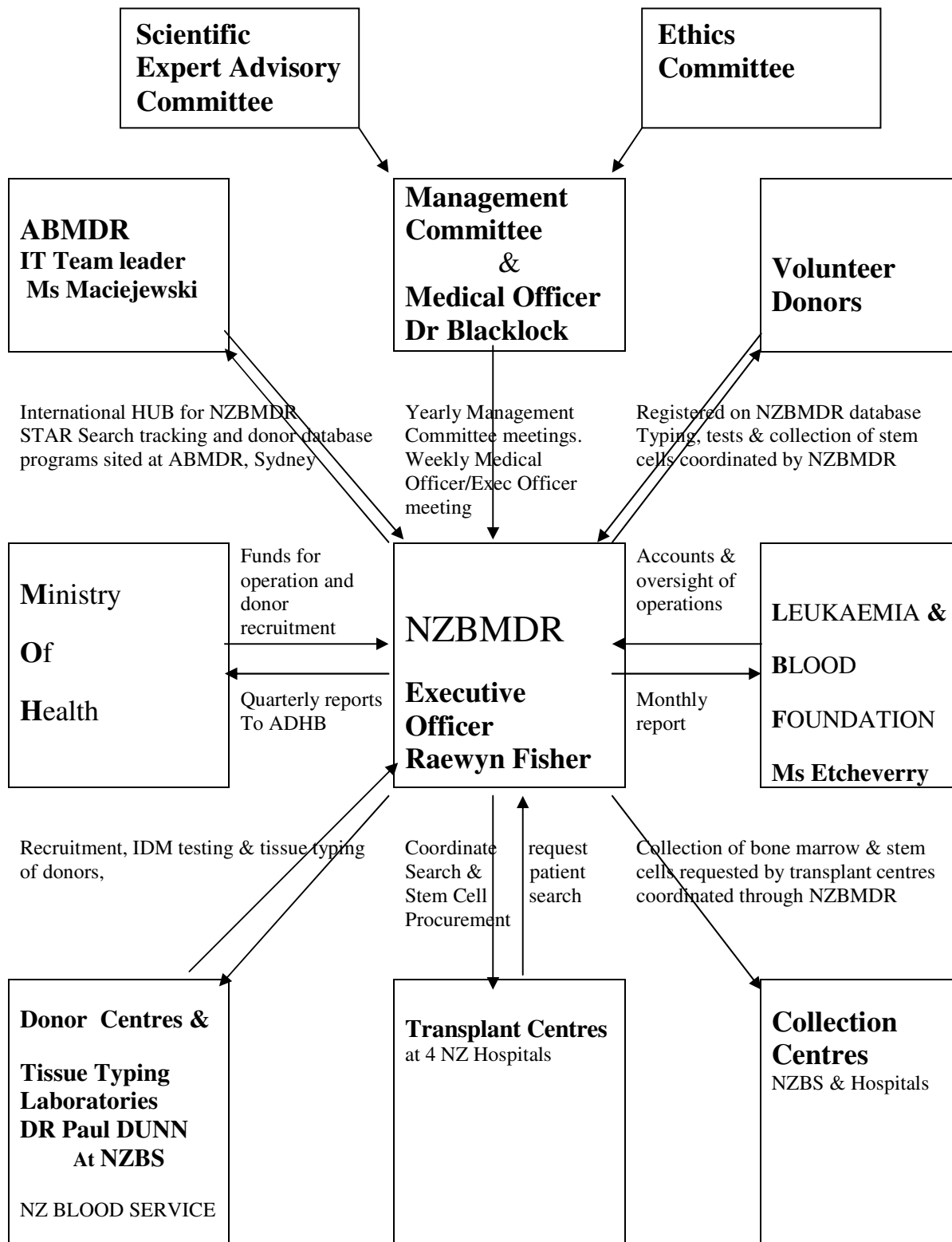
Adult Haematology representative

Paediatric Haematology representative

The committee will be comprised of members who are independent of the patient.

## 2.0

### NEW ZEALAND BONE MARROW DONOR REGISTRY RELATIONSHIPS



## 3.0 Consultants and Advisors to the NZBMDR

### Medical & Scientific Matters

Medical Director <b>Dr Hilary Blacklock</b>	<b>Medical &amp; Ethical issues</b>
--	-------------------------------------

NZBS Donor Centres Medical Director <b>Dr Peter Flanagan</b>	<b>Donor issues &amp; Apheresis Collections</b>
--	---

Transplant/Search Haematologist Chair NZBMTSG <b>Dr Leanne Berkhan</b>	<b>Adult patient &amp; Bone Marrow Collections</b>
---	--

Transplant/Search Paediatric Haematologist <b>Dr Lochie Teague</b>	<b>Paediatric Patient &amp; Cord Blood</b>
---	--

Tissue Typing Head of Department <b>Dr Paul Dunn</b> Technical Specialist Molecular Genetics <b>Laura Hammond</b>	<b>Histocompatibility</b>
--	---------------------------

ABMDR National Office <b>Sally Gordon</b> <b>Lauren Orloff</b>	<b>Search &amp; donor workflow</b>
--	------------------------------------

Members of NZBMTSG	<b>Medical review panel</b>
--------------------	-----------------------------

### Administration

Business Administration LBF Executive Director <b>Ms Pru Etcheverry</b>	<b>Administration &amp; Ministry of Health contracts</b>
---	--

ABMDR IT Manager <b>Anna Maciejewski</b>	<b>IT software STAR</b>
---	-------------------------

NZBS IT Manager <b>Tony Carpenter</b>	<b>IT hardware general software</b>
--	-------------------------------------

LBF accountant <b>Sophie Chen</b>	<b>Accounts</b>
--------------------------------------	-----------------

Knight Coldicutt <b>Geraldine Knox</b>	<b>Legal</b>
---	--------------

ISL Insurer Services Ltd <b>Robert Cormack</b>	<b>Insurance</b>
---	------------------