

Title:

**Section 1.0 NZBMDR STANDARDS  
INTRODUCTION**

Authorised by:

Executive Officer

Contributing Authors:

Dr Hilary Blacklock

Raewyn Fisher

Carolyn Crump

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# 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 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 HLA matched related donor**. Matched unrelated 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. More recently, the availability of a donor has expanded. In some cases if the patient has a healthy child, parent or sibling who is partly matched they may be suitable as a donor— this type of stem cell procedure, known as a haploidentical transplant is becoming more common

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 HLA matched with the recipients, could lead to successful transplants and a cure for chronic myeloid leukaemia (CML).

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

In 1997 the Blood Transfusion Trust entered into an agency agreement with the Leukaemia and Blood Cancer Foundation (LBC) authorising the LBC to operate 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 LBC signed a Letter Of Understanding re the operations of NZBMDR by LBC, now known as the Leukaemia and Blood Cancer New Zealand (LBCNZ)

Annual reports are to be provided by the NZBMDR National Management Committee, to the Ministry of Health via Auckland District Health Board (ADHB), (LBCNZ) and the NZBS. Contract Performance Monitoring Returns are sent to the Ministry of Health quarterly.

The NZBMDR consisting of a national register of donors, is the link between the clinical transplant units and the 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).

NZBMDR was accredited by (WMDA) World Marrow Donor Association in May 2006. Accreditation was renewed with an onsite accreditation visit in June 2012 and December 2016

In December 2008 an Occupation Licence was signed between NZBS and NZBMDR formalising the existing arrangements for occupation of an office within the NZBS complex. This Licence is extended on a yearly basis

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

The postal address is  
P O Box 74336  
Auckland 1546

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  
0800 800 256  
[nzbmdr@nzblood.co.nz](mailto:nzbmdr@nzblood.co.nz)

The LBCNZ is responsible for administering the NZBMDR and managing the financial aspects.

A formal link exists between the LBCNZ on behalf of the NZBMDR and the Australian Bone Marrow Donor Registry (ABMDR) who provide international access to NZBMDR by listing NZ donors on the ABMDR Matchpoint database .  
ABMDR also provide IT programs for donor and patient search algorithms

The MOH is responsible for national policy and funding. A contract for provision of service exists between the LBCNZ and the MOH

## **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
Medical Director of NZ Blood Service	Dr Sarah Morley
NZBMTSC (New Zealand Bone Marrow Transplant Study Group) representative	
APHIA (Asia, Pacific, Histocompatibility and Immunogenetics Association) representative	NZBS Tissue Typing Director
Pediatric Haematology representative	Dr Lochie Teague
LBCNZ Executive Director	Peter Ferguson
National NZBMDR Executive Officer	Ms Raewyn Fisher
NZBMTSG chairperson	
Paediatric Haematology representative	Dr Lochie Teague

## 1.3 ETHICS COMMITTEE

### 1.3.1 Ethical Appraisal of Activity

The NZBMDR will apply to the Auckland Ethical committee 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 committees, before applying to their relevant ethics committee.

## **MEDICAL REVIEW PANEL**

### **1.4.1**

#### **Terms of Reference**

To advise the National Management Committee on:

- All aspects of tissue typing technology. Level of HLA Matching
- 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.
- 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.

#### **1.4.2 Membership**

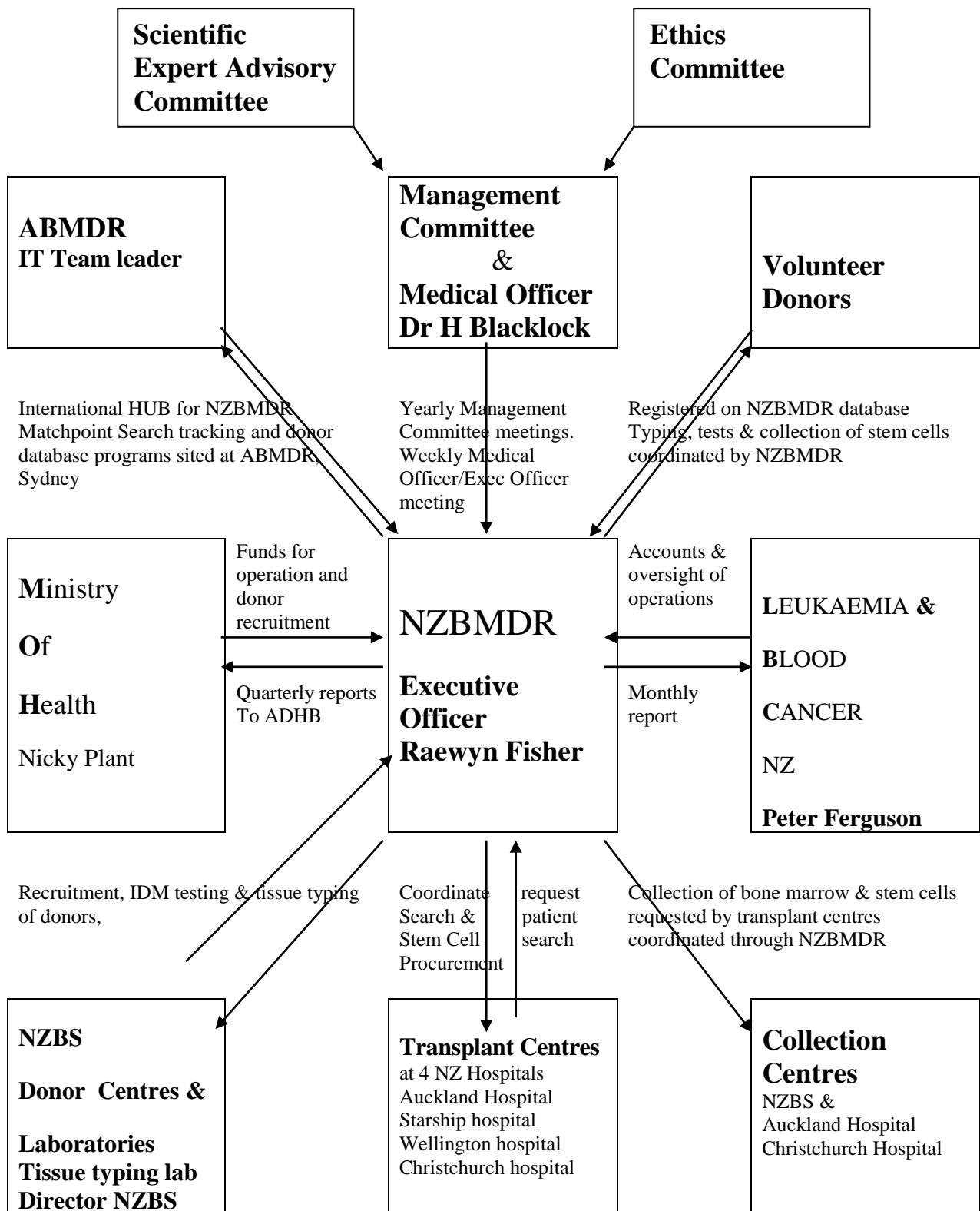
Medical Director

Adult Haematology representative

Paediatric Haematology representative

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

# NEW ZEALAND BONE MARROW DONOR REGISTRY RELATIONSHIPS



## Consultants and Advisors to the NZBMDR

### Medical & Scientific Matters

Medical Director <b>Dr Hilary Blacklock</b>	<b>Medical &amp; Ethical issues</b>
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NZBS Donor Centres Medical Director <b>Dr Sarah Morley</b>	<b>Donor issues &amp; Aphereisis Collections</b>
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Transplant/Search Haematologist Chair NZBMTSG	<b>Adult patient &amp; Bone Marrow Collections</b>
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Transplant/Search Paediatric Haematologist <b>Dr Lochie Teague</b>	<b>Paediatric Patient &amp; Cord Blood</b>
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Tissue Typing Head of Department <b>Dr Heather Dunckley</b>	<b>Histocompatibility</b>
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ABMDR National Office <b>Garth Healey</b>	<b>Search &amp; donor workflow</b>
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Members of NZBMTSG	<b>Medical review panel</b>
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### Administration

Business Administration LBCNZ Executive Director <b>Peter Ferguson</b>	<b>Administration &amp; Ministry of Health contracts</b>
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ABMDR IT Manager <b>Ian Brennan</b>	<b>IT software Matchpoint</b>
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NZBS IT Manager <b>Tony Carpenter</b>	<b>IT hardware general software</b>
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LBC accountant <b>Sophie Chen</b>	<b>Financial management</b>
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Knight Coldicutt <b>Geraldine Knox</b>	<b>Legal</b>
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ISL Insurer Services Ltd	<b>Insurance</b>
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# NZBMDR

## Strategic Plan 2021

**Safety is our Cornerstone**

*Ko te haumarū ta matau matapono taketake*



IT IS ESSENTIAL THAT ALL ACTIONS OF THE STAFF OF NZBMDR CONTRIBUTE TO THE SAFETY OF DONORS, PRODUCTS AND THE RECIPIENTS OF SERVICE PROVIDED TO DONORS AND PATIENTS IN NEW ZEALAND, AND ALSO TO THE PATIENTS OVERSEAS THAT RECEIVE STEM CELL DONATIONS.

In doing this we commit to the following values:

- Striving for Excellence *Kia tau kite Tihi*
- Teamwork *Te Mahi Ngatahi*
- Integrity and Respect *Te Pono me Te Tika*
- Open Communication *Te Whakawhitiwhiti Whakaaro i runga i te Maharahara*
- Safety for All *Te haumarū hoki te katoa*

### **Commitment to the Treaty of Waitangi**

*Te Herenga kite Tiriti of Waitangi*

**NZBMDR AND NZBS RECOGNISE THE PARTICULAR RELATIONSHIP OF NZ MAORI AS *TANGATA WHENUA* WITH THE CROWN, AND ARE COMMITTED TO OBLIGATIONS TO MAORI UNDER THE TREATY OF WAITANGI.** \_\_\_\_\_

In 1996 it was observed that Maori only had a 30% chance of finding an unrelated bone marrow donor whereas non-Maori patients had a 70% chance. Since then, recruitment of Maori (and Pacific Island) Donors, has led to the achievement of equity of access. The development of the NZ Bone Marrow Donor Registry within NZ was the only way to serve the population.

The NZBMDR was formed with the help of Haematologists, government representatives, as well as Members of the Leukaemia and Blood organization (now known as Leukaemia and Blood Cancer NZ).

NZBS, which has stewardship of Bone Marrow under the NZ Public Health and Disability Act, granted an Agency Agreement to the Leukaemia Blood Foundation (LBF later becoming the Leukaemia and Cancer Foundation LBC) to manage the development and administer the registry. Close association with LBC, NZBS, ABMDR, Department of Health and the DHB Haematologists ensures that the registry adequately serves all patients requiring a bone marrow transplant. Operational activities are overseen by NZBMDR who work on a cooperative basis with these groups:

**LBC** Oversight of Government regulations including staff of NZBMDR and Finance.

**NZBS** Accommodation of HUB office and supply and maintenance of general IT software.

Donor recruitment of Blood Donors to NZBMDR. Health Screening of all blood donors  
Tissue typing.  
Collection of Apheresis products. Storage of Cryopreserved products

**ABMDR** Supply, advise and maintain IT services associated with a donor database “Matchpoint”

## **HAEMATOLOGY CONSULTANTS**

Regular communication with DHB Haematologists regarding the need for a stem cell donor for patients who require a Stem cell/marrow transplant.  
Collection of Marrow stem cells

## **DEPARTMENT OF HEALTH**

Three monthly public funding  
Monthly operational management report

## **OPERATIONAL OBJECTIVES**

### **Background to future development of NZBMDR**

Several changes in the health of the NZ population since the introduction of Covid-19 has led to a change in priorities and strategies for the future

Up until 2020 recruitment of donors has largely been through the NZBS donor centres where donors have been introduced to the idea of extending their commitment as a volunteer blood donor to include registering as a potential bone marrow donor.

Recruitment of ethnic minorities, in particular Maori and Pacific islanders, has been and remains a top priority.

However the ethnic mix of the NZ population has become more diverse with a significant percentage of Asian people

Advances in HLA tissue typing leading to high resolution as the norm when new donors are recruited has changed the work emphasis from requests for HR to a greater amount of time arranging for collections of HPC and distribution of product overseas.

### **Planned changes and objectives**

To achieve success in this new environment we are planning the following changes.

- 1) The age of donors at recruitment will be reduced to 18 to 30 years.
- 2) This age range will be extended to 18-59 for any donor who has been tissue typed eg as a family member, or is transferring from another Registry.
- 3) Emphasis will be to recruit males
- 4) Increase recruitment of NZBS donors by visits to all NZBS donor centres
- 5) More effort for recruitment will be through ethnic groups such as Maori whanau, Pacific Island and Asian churches
- 6) Development of student groups
- 7) Initial tissue typing of groups outside NZBS will use Buccal swabs with testing being carried out by Histogenetics.
- 8) All tissue typing after initial recruitment will be performed by NZBS
- 9) Raise Public awareness of the contribution that donor, registries and transplantation make to improving the health of patients