

Title:

**Section 1.0 NZBMDR STANDARDS
INTRODUCTION**

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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 Foundation (LBF) authorising the LBF 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 LBF signed a Letter Of Understanding re the operations of NZBMDR by LBF, 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

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Epsom, AUCKLAND 1051

The postal address is

P O Box 74336

Auckland 1546

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Fax: +64 9 5235757

Mobile available 24 hours 0274 588661

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 Peter Flanagan
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	Ms Pru Etcheverry
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

NZBMTSG chairperson

NZBS representative

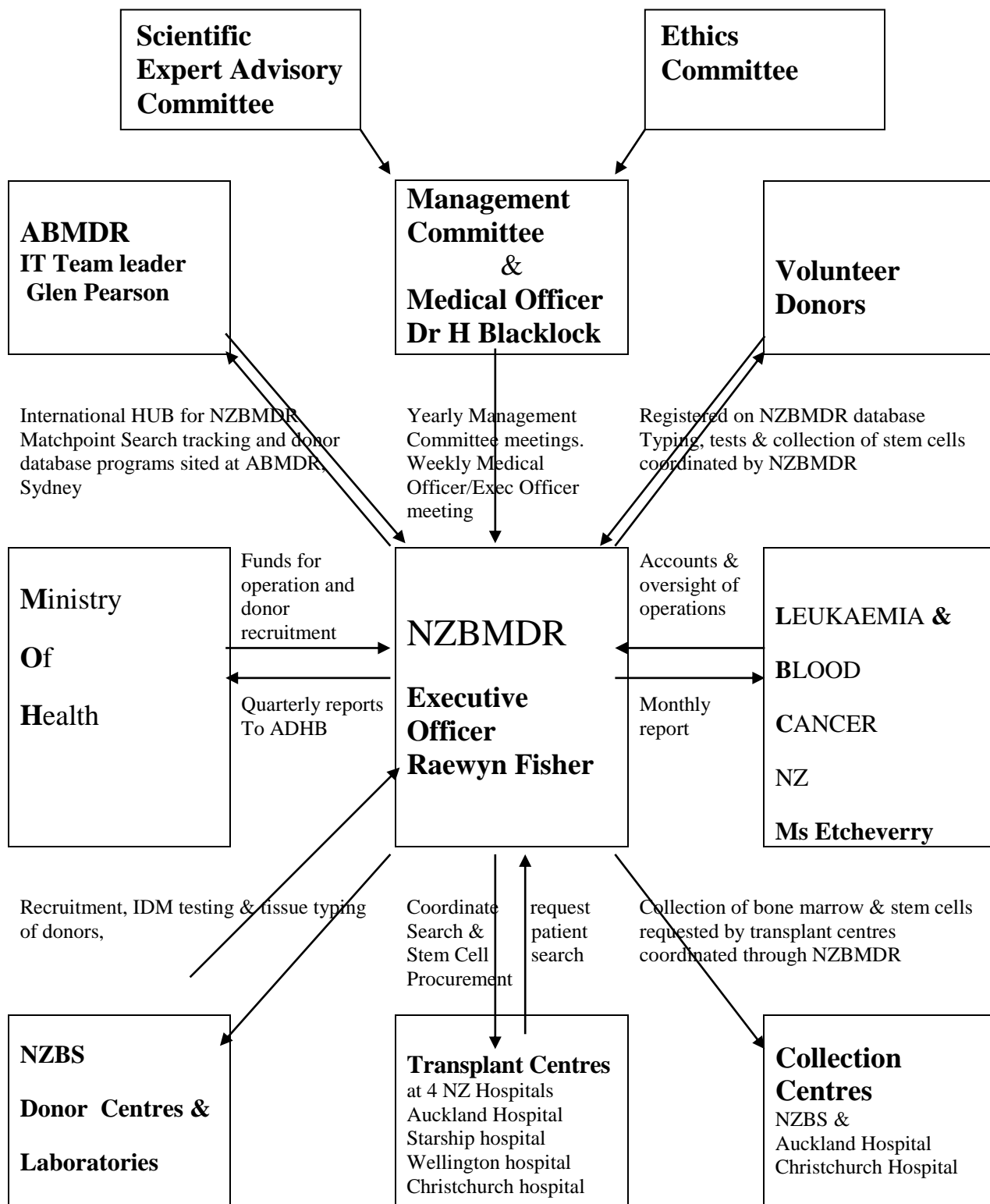
Adult Haematology representative

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



**Director NZBS
TT Lab**

3.0

Consultants and Advisors to the NZBMDR

Medical & Scientific Matters

Medical Director Dr Hilary Blacklock	Medical & Ethical issues
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NZBS Donor Centres Medical Director Dr Peter Flanagan	Donor issues & Apheresis Collections
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Transplant/Search Haematologist Chair NZBMTSG	Adult patient & Bone Marrow Collections
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Transplant/Search Paediatric Haematologist Dr Lochie Teague	Paediatric Patient & Cord Blood
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Tissue Typing Head of Department Dr Heather Dunckley	Histocompatibility
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ABMDR National Office Anthony Montague	Search & donor workflow
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Members of NZBMTSG	Medical review panel
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Administration

Business Administration LBCNZ Executive Director Ms Pru Etcheverry	Administration & Ministry of Health contracts
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ABMDR IT Manager Glen Pearson	IT software Matchpoint
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NZBS IT Manager Tony Carpenter	IT hardware general software
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LBC accountant Sophie Chen	Financial management
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Knight Coldicutt Geraldine Knox	Legal
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ISL Insurer Services Ltd Robert Cormack	Insurance
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