

Title:

**SECTION 17.0 NZBMDR STANDARDS
PUBLIC RELATIONS AND
CONFIDENTIALITY**

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Forms

Release of Personal Details

NZBS107F05605

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INTRODUCTION

It is recognised by the NZBMDR that publicity is essential for the ongoing interest in, commitment to, and success of the NZBMDR.

However, confidentiality of both donor and recipient is of paramount importance and hence the timing of publicity is critical.

Transplant and Donor Centres must be aware of the potential for conflict between recipients' families and donors. Recent protocols have increased the frequency of requests for blood products following a Stem cell Transplant. Conflict has been caused in other registries by a refused request for a second donation in the event of graft failure, and misunderstanding and blame apportioned by a family to a donor following death of a recipient. Private investigators have been used to detect the identity of unrelated donors. The serious import of these issues cannot be understated.

This standard has been compiled in an effort to achieve a reasonable compromise between these two essential components of the Registry and to provide guidelines to ensure a satisfactory outcome in this area.

17.1 GENERAL PRINCIPLE

No media publicity surrounding the patient or donor may take place within 3 months post transplant. Confidentiality is paramount as cited in the section following. After this time, with the express written permission of the donor and/or the recipient and at the NZBMDR Executive Officer's & Transplant Physician's discretion, either party may be involved in publicity, refer Form NZBS107F05605

This does not preclude general press statements that stem cell transplants are being performed

17.2 PUBLIC RELATIONS

17.2.1 Local Donor Centre Publicity

Local Centres are responsible for their individual public relations as they relate to the functioning of the NZBMDR. Local Centres may not make official comment on behalf of the NZBMDR nor on international relations without prior express written consent from the NZBMDR Executive Officer.

All press releases should be sent to the NZBMDR, as soon as practical, for approval and dissemination to other centres that may be affected by their release.

17.2.2 National and International Statements

The National Management Committee (NMC) is responsible for all national and international statements on the functioning of the NZBMDR.

17.2.3 Matched Donor Publicity

A matched donor can be asked whether he or she is prepared to assist in publicity.

If donors are agreeable to publicity, **confidentiality must be maintained by using the first name only** of the donor in any press release.

There must be adequate discussion and explanation to donors, to ensure that they are aware of what is involved in publicity and the fact that media reporting may not always be factual.

Written consent must be obtained prior to publicity by NZBMDR or NZBS.

Refer: NZBS Publicity Consent Form NZBS107F05605

17.2.4 Transplant Publicity in General

On behalf of the NZBMDR, the National Management Committee may release general press statements to media outlets concerning stem cell donation. **There must be no identification of either donor or recipient.**

If a human interest story is pursued by the press, information on a transplant performed more than three months previously could be used with the written permission of the relevant parties, refer-Form PR001. **The Transplant Centre involved must be informed of the intention of the NZBMDR to issue such a statement and must agree in writing.**

17.3 DONOR AND PATIENT CONFIDENTIALITY

Refer to the WMDA paper for reasons behind the following policies.
Education, WMDA recommendations, Confidentiality Donor - Patient

Disclosure of any information about either donor or recipient human tissue is strictly forbidden, unless with the written consent of the person to whom the information relates.

Non-identifying details of prospective donors can be released to the Transplant Centre after the donor's intent to donate HPC has been made in writing. This is signed at the time a third party haematologist provides an information session to the donor. Each Donor, Collection and Transplant Centre is responsible for limiting access to confidential information and for reminding its staff with access to this information, of their responsibility to maintain full confidentiality.

17.3.1 Donor Anonymity

- i] To protect donor anonymity, the **location of the donor** must never be disclosed to the patient or the patient's family. This information must not be disclosed to anyone at the Transplant Centre who cannot comply with the strict need for confidentiality. To protect donor anonymity **at the time of stem cell delivery**, the stem cells should have no identifying markings other than the unique donor identification number.

ii] **Responsibilities regarding Stem Cell Couriers (in relation to Donor Anonymity)**

The patient's family, Transplant Centre, or Collection Centre staff, should not question the courier about where they have come from, or the identification of the donor.

- iii] Any correspondence from the donor to the patient must go through the NZBMDR, to screen and remove information that directly identifies the donor or patient, before passing it on to the patient. (if the correspondence is appropriate).

17.3.2 Patient Anonymity

- i] To protect patient anonymity, Donor Centres must **never disclose the patient's name** to the potential donor. Donor Centres **should not disclose the location of the patient's Transplant Centre** to the donor.

- ii] If stem cells are to be donated by a New Zealand donor to an overseas patient, it is reasonable to inform the donor of the continent in which the patient resides.

- iii] To protect patient anonymity, any patient-generated correspondence or gifts that the patient may want to give to the donor must go from the Transplant Centre to the NZBMDR, who will screen the item before sending it on to the donor, if appropriate. The patient should be informed of any components that may be removed.

- iv] The level of patient information released to the donor must only include the continent the patient comes from, whether the patient was an adult, child or teenager, sex of the patient, and the fact that they were suffering a life-threatening blood disorder.

v] Responsibilities regarding the courier (in relation to Patient Anonymity)

The courier must not make a request to meet the transplant recipient or their family. If the recipient or the recipient's family wishes to meet the courier this may be facilitated through the collection or Transplant centre. However the courier must not disclose the donor collection centre or personal details about the donor.

17.4 DONOR/RECIPIENT MEETINGS

No meeting between the donor and recipient will be facilitated by the NZBMDR. No contact details will be released to the other party.

Correspondence with no personal identifiers may be exchanged through NZBMDR

If the patient and donor are in the same New Zealand institution, they must be placed in different wards, but ideally they should be in separate institutions.