Title:	**Section 15.0 NZBMDR STANDARDS STEM CELL DONOR RETIREMENT AND FOLLOW UP**
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SECTION 15.0 NZBMDR STANDARD STEM CELL DONOR RETIREMENT AND FOLLOW-UP

15.1 ENROLLED DONOR FOLLOW-UP

The NZBMDR will maintain regular contact if possible, with enrolled donors. The contact will check their continued willingness and ability to donate and seek any change of contact details. A second contact number of a friend or relative, who does not live with the donor but is likely to know the donor's whereabouts, should be kept.

15.2 STEM CELL DONOR FOLLOW UP

i] Donors must be contacted by NZBMDR within 72 hours of the donation of Stem Cells or other blood products and the phone call recorded on Form 70.

Refer: Form 70 Donor Evaluation Immediately Post-Donation

Donors must then be contacted weekly until fully recovered and comments recorded on Form 76.

ii] Telephone contact should be made at 6 months with blood tests requested from apheresis donors.

iv) If the donor has indicated that they wish to have updates on the progress of their patient this may be passed on at the same time. .

vi) If any donor health issue that may have relevance to the patient arises e.g. malignancy, NZBMDR Medical Officer must inform the Transplant Centre HUB in writing.

vii) After donation, donors will be retired from the Registry for 12 months. Contact should be made at 12 months to check on their general wellbeing and to invite them to join the Registry again if they so wish.

Refer: Form 77 HPC Donor Long term Follow up (page 1)

(vi) If at 12 months the donor has no health issues related to the HPC donation a telephone consultation will be held each year for the following 9 years.
Any health issues related to the HPC collection which are identified during these telephone consultations will be followed up by the medical officer
All costs for treatment will be covered by ACC or the hospital's insurance policy

15.3 G-CSF HPC, APHERESIS DONOR FOLLOW UP

i) In addition to Form 77 a Full Blood Count and Blood Chemistry will be performed at 6 months. If all counts are back to normal no further blood counts are required.
ii) If blood counts are not normal the medical officer will decide on appropriate follow up action.

15.4 SECOND OR SUBSEQUENT DONATIONS

Donors should be informed at workup that they may be asked for a second donation for the same patient. This information is also included in the information brochure read at recruitment.

Bone marrow donors can donate blood if they have completely recovered

After an HPC, Marrow donation - six (6) months
After a G-CSF stimulated HPC, Apheresis donation - six (6) months
After donating unstimulated Lymphocytes – three (3) months

i] Second Donation for the Same Patient

Follow up should occur as for a first donation.

ii] Second Donation for a Different Patient

Donation of GCSF stimulated HPC, Apheresis for a different patient will not be considered unless the donor is the only potential donor in the world for a patient

15.5 DONOR RETIREMENT

i) Donors are automatically retired on their 60th birthday.

ii) Donors should also be retired if they fail to respond to contact procedures for two years.

iii) Donors should be retired from the registry for six months post childbirth or later if still breastfeeding.

iv) No donation may take place if the donor is pregnant or is breast feeding.

v) If the donor has passed the retirement age but is the only matched donor, requests for a second or subsequent donation (for the same patient) of lymphocytes or stem cells can be considered by the panel of three haematologists, on a case by case basis

vi) After bone marrow donation, donors will be retired from the Registry for 12 months.

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15.6 SERIOUS EVENTS AND ADVERSE EFFECTS REGISTRY (SEAR)

The Serious Events and Adverse Effects Registry (SEAR) is an anonymous central reporting system of the World Marrow Donor Association (WMDA) Its goal is to obtain insight into the occurrence of any serious events and adverse effects in relation to stem cell donation by unrelated donors. Comprehensive, confidential and anonymous reporting is fundamental to the success of this scheme. The clinical committee of the WMDA will present the SEAR data annually to the WMDA board, who will report the results to the members of WMDA.

The NZBMDR has a Donor Incident Report which should be completed in addition to the SEAR report. This report should be used for any incident, and sent to the NZBMDR National Office regardless of whether it is appropriate for SEAR or not.

Refer: Form DIR: NZBMDR Donor Incident Report
www.worldmarrow.org

What to Report

General Principles
Any untoward medical event that in the opinion of the reporting registry:

1. results in death;
2. is potentially life threatening;
3. requires in-patient hospitalisation or prolongation of existing hospitalisation;
4. results in persistent or significant disability/incapacity.

In addition to these general principles, the following specific events are given as indicators that should be reported:

Specific Issues which should be reported

- **Any serious potential risk during anaesthesia**, even when resolved completely. e.g. profound bradycardia during anaesthesia requiring emergency treatment, laryngospasm during anaesthesia, severe adverse reactions to drugs or IV fluids.

- **Any serous cardiac complication** during or shortly after HPC donation.

- **Any serious infection**
  e.g. Infections beyond local infections of site of HPC, marrow collection or minor line infections, sepsis, osteomyelitis etc.

- **Any serious mechanical injury**
  e.g. Nerve damage from marrow collection or IV lines, damage to SI joint, fractures of iliac crest, retroperitonal haematoma or injuries etc.

- **Any serious haemostatic incident**
  e.g. thrombosis, embolism after HPC, marrow or HPC, apheresis harvest, abnormal bleeding secondary to thrombocytopenia complicating HPC, apheresis harvest.

- **Any serious (late) effect of HPC, Marrow or HPC, Apheresis donation**
  e.g. A flare of a systemic disease (lupus) after marrow donation, a haematological disease reported following growth factor administration.

This listing is not considered complete and every effort to prevent under reporting should be avoided. The Clinical Committee is responsible for analysis and presentation of the annual data collection.

SEAR and SPEAR reports are available on the WMDA website and will be completed on line

15.7 PATIENT PROGRESS INFORMATION FOR DONORS

Many donors like to have some feedback as to the patient's progress post-transplant. Form PP001 should be used for this purpose.

Refer: Form PP001: Patient Progress Report