SABMR
SOUTH AFRICAN BONE MARROW REGISTRY
Registered as a Nonprofit Organisation:
Reg No: 004-300 NPO

South African Bone Marrow Registry
J57, Old Outpatient Department
Groote Schuur Hospital, Observatory, 7925
Cape Town, South Africa
Tel: +27-21-447-8638
Fax: +27-21-404-6395
Medical Director: charlotte.ingram@sabmr.co.za
Email: jane.ward@sabmr.co.za

SEARCH ACTIVATION REQUEST

Date of Activation request: _____ (DD/MM/YYYY)		Is the search urgent? ☐ Yes / No ☐ Mismatches accepted? ☐ Yes / No ☐	
Last name:		First name:	
Date of birth: _____ (DD/MM/YYYY)	Sex: M / Female	Height : _____ m Weight : _____ kg	CMV status: ☐ Unknown ☐ Positive ☐ Negative
Diagnosis:		ICD-10 Code:	Date of Diagnosis: _____ (month / year)
Current disease status:		Estimated date of transplant:	

EXPEDITED SEARCH:

A service offered by the SABMR exclusively for critically **urgent cases** in the interest of time. When ticked "Yes", the SABMR will proceed with testing and verification of the selected unrelated donors in the absence of the medical aid authorisation with the understanding that the Transplant Centre will obtain the required authorisation and/or funds, with similar urgency, prior to stem cell procurement.

Note: Full-panel High-Resolution HLA Typing of the patient is required from the transplant centre at the start of the Expedited Search process.

☐ Yes ☐ No

I (Transplant Physician), ……. acknowledge the financial risk to the SABMR, by incurring costs without the required guarantee of funds, and will endeavor to ensure that the SABMR is re-imbursed.

Signature: ……

VERIFICATION OF PATIENT HLA TYPING:

Fresh blood samples/buccal swabs sent to laboratory or SABMR for testing: ☐ Yes ☐ No Date sent: _____ Date to be sent: _____

WMDA standards require that both patient and donor HLA typing be verified at high resolution on a second blood/buccal swab sample in an EFI/ASHI accredited laboratory.

Medical Aid: _____ Membership No: _____

Authorisation received: ☐ Search Auth ☐ Search/Procurement ☐ Treatment ☐ In progress

NB: Please ensure the Auth is addressed to the SABMR Medical Director, Dr Charlotte Ingram, to avoid any delays further along in the process.

Requesting Physician: ……	**Transplant Centre** ……
Person completing form: ……	**Transplant** Physician: ……
Email: ……	Email: ……
Cellphone: ……	Cellphone: ……

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PATIENT DETAILS			
Name of patient			
ID Number			
Date of birth			
Hospital			
Diagnosis / ICD10 Code			
Home address		**Postal address**	
Cell	**☎ Home**	**☎Work**	**Fax**
E-mail			
Alternate Contact Person (in the event that patient / immediate family cannot be reached)			
Name			
Relationship		**☎ Home**	
Cell No		**☎Work**	
PATIENT MEDICAL AID DETAILS			
Medical Aid			
Medical Aid Number			
Name of Principal Member			
Medical Aid Contact Person			
Medical Aid Address		**E-mail**	
		Tel	
		Fax	
PERSON RESPONSIBLE FOR PAYMENT OF ACCOUNTS (In the event of reimbursement from the SABMR)			
Name			
ID Number (Certified Copy)		**Date of Birth**	
Account Name		**Branch Name / Number**	
Bank			
Account Number		**Note : Banking details to be certified by your bank**	

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PATIENT INFORMATION SHEET

Dear Patient

This information sheet provides you with information on matched unrelated donor searches conducted by the SABMR ("donor searches"). The purpose of this information sheet is to assist you in deciding whether or not you would like the SABMR to conduct a donor search for you.

The SABMR is a local non-profit organisation which was established in 1991 for the purpose of identifying unrelated human leukocyte antigen ("HLA") matched Haematopoietic Stem Cell (HSC) donors for patients who need bone marrow transplants and who do not have relatives that are suitable donors. The SABMR works together with transplant centres locally and internationally in order to ensure that unrelated stem cell donors are identified so that life-saving transplants may be performed on patients. The SABMR is fully accredited member of the World Marrow Donor Association ("WMDA") and therefore the SABMR has access to donor registries worldwide.

You are encouraged to read this information sheet and ask questions at any time before consenting to a donor search and transplant. This document must be read with the document entitled "Informed Consent to Donor Search " (SABMR DOC108). Please note that this document is intended for information purposes only and should in no way be construed as imposing any obligation whatsoever on the SABMR.

WHEN A SEARCH FOR AN UNRELATED DONOR IS BEING CONSIDERED FOR YOU

Prior to determining whether or not you would like the SABMR to conduct a donor search for you, a representative of the SABMR search coordination team ("the representative") can be contacted for general information relating to donor searches, including information on the financing of donor searches, the procurement of medical scheme authorisation for donor searches and the manner in which donor searches are conducted by the SABMR. The information provided to you by the SABMR may be conveyed to you either electronically or during a scheduled telephonic or personal consultation with a representative of the SABMR.

After consulting with the representative and once you have considered all of the information that has been provided to you by the representative, you will be afforded an opportunity to decide whether or not you would like the SABMR to conduct a donor search for you.

INITIATING A DONOR SEARCH

Should you decide that the SABMR should conduct a donor search for you, the healthcare professional with which you have consulted about your condition ("your healthcare professional") will, with your consent, provide the SABMR with your personal details and request the SABMR to conduct a donor search for you. The personal details to be provided to the SABMR by your healthcare professional will consist of, at least, your name, age, gender, HLA typing, diagnosis and any other medically relevant information that will assist the SABMR in finding a donor match for you.

The SABMR will then conduct a preliminary search ("preliminary search") for unrelated donors that may be a potential match for you ("potential donors"). In this regard, the SABMR will first conduct a search on its local database in order to identify potential donors and if unsuccessful, the SABMR will conduct a donor search on the

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international databases for potential donors. The preliminary searches will be conducted by the SABMR at no cost to you or your medical funder.

The results of the preliminary search will be furnished by the SABMR to your healthcare professional for his/her consideration. In this regard, the results presented to your healthcare professional will include information relating to the number of potential donors that have been identified by the SABMR, the degree of suitability of each of the potential donors and whether or not the potential donors have been identified on the local or international registries. Additionally, and if so requested by your healthcare professional, the SABMR will provide your healthcare professional with information relating to cord blood units as the potential donors.

The SABMR will be the sole point of communication between you, your healthcare professional and the transplant centre and any national or international entities involved in the donor search. All search reports compiled by the SABMR will be provided to your healthcare professional, who will be responsible for conveying the contents of the search reports to you.

IDENTIFICATION OF A SUITABLE DONOR

Your healthcare professional will then, in consultation with the SABMR, decide on a donor testing strategy for the potential donors that are identified ("the donor testing strategy"). From this stage onward, you or your medical funder will be required to pay the SABMR for the services rendered by the SABMR in performing the donor search.

The SABMR will proceed to arrange advanced laboratory tests on each of the potential donors in accordance with the donor testing strategy in order to ascertain which, if any, of the potential donors are suitable, available and willing to donate stem cells to you. At this stage, the donor search is termed “activated” and the SABMR will be responsible for:

- confirming the HLA typing of potential donors;
- reporting on the availability of potential donors for confirmation (also known as verification) typing; and
- reporting the results received from the HLA typing laboratory or international donor registry.

The SABMR will provide the results of the advanced laboratory tests to your healthcare professional, who will discuss these results with you. Your healthcare professional will be required to select the donor who he/she determines is the best donor for you ("the donor") and to advise the SABMR of his/her selection. The SABMR will then provide your healthcare professional with information on all aspects of the donation and the potential transplant process, including -

- the availability of the SABMR to meet the preferred transplant date(s) or to negotiate alternative date(s);
- the donation method selected by the donor;
- the donor work-up schedule, which will include dates for counselling of the donor, the medical examination of the donor, the outcome of medical assessment of the donor and details regarding the proposed HSC collection; and
- any potential temporary or permanent donor deferral reasons which may result in the postponement or cancellation of the transplant.

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Should you elect to proceed with the transplant, the SABMR will coordinate all of the logistics for the collection and harvesting of the donor stem cells by a specialised collection centre ("the collection centre") in South Africa. If a potential donor is identified in an international registry, the international registry will be responsible for selecting a suitable collection centre abroad. Collection centres are health establishments responsible for the collection of the stem cells from donors. The collection centre will not guarantee that the necessary total number of nucleated cells (bone marrow) or CD34+ cells (peripheral blood stem cells) required for your transplant will be collected from the donor as the safety of the donor will take precedence over the optimal collection of the stem cells from the donor. Once the stem cells have been collected by the collection centre, the SABMR will proceed with the arrangements for the stem cells to be transported to the transplant centre. In this regard, the SABMR follows guidelines published by the WMDA for the purpose of transporting donor stem cells. The SABMR will notify the transplant centre of the expected date and time of arrival of the stem cells at the transplant centre.

Additionally, after the transplant, your healthcare professional will be required to advise the SABMR of the quality of the stem cells delivered to the transplant centre, any adverse reaction or event relating to the infusion of the HSC and the outcome of the transplant.

FINANCING OF THE DONOR SEARCH

The SABMR is a non-profit organisation, but does not pay for the total costs of finding a donor. A free preliminary search for potential donors is provided. A fee is, however, charged for the remainder of the services that the SABMR performs in relation to the donor search. If you have medical aid and if your medical aid agrees to fund the donor search, you or your healthcare professional will be required to obtain pre-authorisation for the donor search by your medical aid. You are required to ensure that you are able to cover any costs that your medical aid does not cover. If you do not have medical aid, please speak to us about the costs for each phase of the donor search process so that you know how much you will be required to pay for the donor search. In general, you must pay us in advance for each phase of the donor search which we are required to perform. This is because we incur expenses in paying our national and international partners to search for and test possible donors for you. Fees paid to us may be transferred into an interest bearing bank account. If there is any interest that is earned between you paying us and us paying the expenses, the interest will be used by us to cover administration expenses. Any interest on the fee will, therefore, not be refunded to you.

Should you decide that you would like the SABMR to conduct a donor search for you, you will be required to pay the following fees in respect of each phase of the donor search:

- Search Activation: This is a once-off, professional fee charged by the SABMR and some international registries at the time that donor testing is requested;
- Extended Donor Testing: These fees are for conducting the necessary additional HLA typing and other testing required to establish if the donor is a suitable match;
- Verification Typing: This fee is for the mandatory verification typing of the donor. A fresh blood sample (adult donors) or archived DNA sample (for cord blood units) will be tested to verify the initially reported donor HLA typing. At this stage, infectious disease marker testing is also conducted on adult donors;

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- Stem Cell Collection: A global fee is determined by all donor registries for the collection stem of cells. In addition, you will be required to pay the costs of transportation of the stem cells from the donor centre to the transplant centre

DONOR-RECIPIENT CONTACT

Should a donor be identified during the donor search and to the extent that you elect to undergo a transplant, you may anonymously correspond with your donor - through the SABMR. You are encouraged to prepare a letter of thanks for your donor. The letter of thanks should not include your personal details. Additionally, no photographs should be exchanged between you and your donor and the exchanging of gifts is prohibited. Prior to transplantation, your donor will be provided with a limited amount of information about you including general information about your age, diagnosis and country in which the transplant will be performed. Direct contact with your donor is subject to the conditions imposed by the donor registry. The SABMR policy on donor-recipient contact is available on request.

PUBLICITY

SABMR's privacy policy is implemented in order to protect the anonymity of the transplant process. In terms of the SABMR's privacy policy, a transplant may only be publicised three months after the transplant has taken place and any such publicity may not include the date of the transplant or the city in which the transplant was performed.

Signed at: ……

……
Signature of patient

Date: ……

……
Name of patient (in block capitals)

Signed at: ……

……
Signature of guardian where patient is a minor

Date: ……

……
Name of guardian (in block capitals)

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Complete if the patient is not fluent in English and an interpreter was used to translate this information sheet:

Signed at: ……

Date: ……

……

Signature of interpreter

……

Name of interpreter

I confirm that this information sheet was orally translated for me by the interpreter in a language that I understand, being ……. (state language).

……

Signature of patient

……

Name of patient (in block capitals)

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INFORMED CONSENT TO DONOR SEARCH

1. I, ..., with identity number ..... ("patient"),

[Patient name in block letters]

hereby acknowledge that I have received information regarding the donor search procedures conducted by the South African Bone Marrow Registry ("donor searches") by a representative of the Transplant Centre, being ..... and that the nature and object of the donor searches, together with the benefits, possible risks, costs and consequences generally associated with donor searches, were explained to me to my satisfaction by the representative.
I was given the opportunity to ask any questions relating to donor searches and I received satisfactory answers from the representative to my questions; and I hereby irrevocably give my express and informed consent to participate in a donor search to be conducted by the SABMR.

2. THE DONOR SEARCH

I acknowledge that the SABMR may have access to and use all of my confidential, medical, personal, financial and other information necessary in order properly to conduct the donor search ("health records") and that I provided accurate information about my health and medical history. A suitable donor is not guaranteed, and I hold no entity liable if no donor is found. If a suitable donor is found, I shall not contact the donor directly and all correspondence with said donor will be via the SABMR.

I have been counselled by the representative regarding the financing of donor searches. I, accordingly, understand that I or my medical funder am responsible for the costs incurred as a result of the donor search. Should I be eligible for Financial Assistance I will provide honest and accurate information to qualify

3. PROTECTION OF PERSONAL INFORMATION ACT 4 OF 2013

I acknowledge that I am a 'data subject' in terms of the Protection of Personal Information Act 4 of 2013 ("POPIA").
I confirm I am aware of my rights as a data subject in terms of section 5 and 18 of POPIA. I am aware that I may approach the SABMR for more information on how the personal information provided in this form is processed.

The purpose of the processing of my personal and special personal information

I understand that the personal information contained in this form, as well as any information relating to my confidential medical, personal, financial and other information is provided to SABMR to facilitate a search for a donor and that the information will be processed to give effect to this purpose.

I declare that my signature on this form shall constitute proof of my consent in terms of section 11 (1) (a) of POPIA to the processing of my personal and special personal information for this purpose.

Patient/Guardian Initial

For further information relating to POPIA, your rights in terms of POPIA and the SABMR's POPIA policy, please note the following resources:
POPIA: https://www.gov.za/sites/default/files/gcis_document/201409/3706726-1act4of2013protectionofpersonalinforcorrect.pdf
https://sabmr.co.za/privacy-statement/

4 WAIVER AND INDEMNITY

Except to the extent that the SABMR acts with gross negligence or fraudulent intent in respect of the donor search I hereby waive all claims of whatsoever nature and howsoever arising which I may have against the SABMR in connection with or related to the donor search, including, without limiting the generality of the aforegoing, claims arising out of any direct or indirect effects which I may suffer as a result of the use by the SABMR of my health records, any medical tests performed on me, the matching of a donor and the collection, transportation, storage and harvesting of a matching donor's stem cells; and

I Agree to indemnify the SABMR and to hold it harmless against any claim which may be instituted by any third party from any cause arising out of the donor search as contemplated in clause 4.1, including, without limitation, any claim instituted by my dependants.

CONFIDENTIALITY

The SABMR undertakes, subject to paragraph 2, to keep confidential and not to disclose to any third party the nature or content of the health records and test results, in particular, and information, in general, which they receive

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from me from time to time, except insofar as is required in terms of the purpose outlined above.
The SABMR and I undertake to keep confidential and not to disclose to any third party any information relating to the transplant within three months from the date upon which the transplant has taken place.

After the three-month period referred to in paragraph 5, certain information relating to the transplant (excluding information relating to the date of the transplant and the city in which the transplant was performed) may be publicised by me and/or the SABMR to third parties.

Notwithstanding paragraph 5, the existence and contents of the information referred to in the aforementioned paragraphs, may be disclosed to:

- the extent agreed to between the SABMR and me.
- the extent required by law (other than in terms of a contractual obligation)
- the SABMR for research to improve the haematopoietic stem cell transplantation and donation process.

CONSENT

I have had an opportunity to receive and read (or have explained or read to me in a language that I understand) and I fully comprehend the terms, conditions and consequences of this consent form. I have been made aware of all the terms printed in bold by the representative; and have had sufficient opportunity to ask questions about this consent form and have had these questions, if any, answered to my satisfaction by the representative.

My consent to the terms is provided of my own free will without any undue influence, and I have been provided with a signed copy of this form by the representative.

My signature below indicates my understanding of, and agreement to, comply with the terms of this ***consent form.***

DISCLAIMER:

My informed consent, in terms of this consent form, relates only to the conduct of the SABMR in relation to the donor search. Any ancillary consent which I am required to give for the purpose of a transplant will be provided by me in separate consent forms, which are to be read together with this consent form.

Signed at: ……

Date: ……

……

Signature of guardian where patient is a minor

……

Name of guardian (in block capitals)

Complete if the patient is not fluent in English and an interpreter was used to translate this information sheet:

Signed at: ……

Date: ……

……

Signature of interpreter

……

Name of interpreter

I confirm that this information sheet was orally translated for me by the interpreter in a language that I understand,

being……. (state language).

Name of patient (in block capitals)……

Signature of patient……