

支持拯救生命 Support Saving Life

骨髓配對及捐贈資訊

Educational pack for Confirmatory Typing and Workup



香港骨髓捐贈者資料 HONG KONG BONE MARROW DONOR REGISTRY



内容:

骨髓配對及捐贈資訊

Educational Pack for Confirmatory Typing and

P.3 - P.19

私隱聲明

Privacy Policy Statement P.20 - P.27

個人資料收集聲明 - 捐贈者

Personal Information Collection Statement- Donors P.28 - P.32



Educational Pack for Confirmatory Typing and Workup



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香港骨髓捐贈者資料庫背景

香港骨髓捐贈者資料庫(HKBMDR)由香港紅十 字會輸血服務中心(HKRCBTS)管理及營運, 是香港唯一的無血緣骨髓捐贈者資料庫,為本 地及全球需要接受造血幹細胞移植的患者搜尋 合適的捐贈者。請登記成為骨髓捐贈者,您也 有機會成為拯救生命的英雄!

1. Hong Kong Bone Marrow Donor Registry **Background**

Hong Kong Bone Marrow Donor Registry (HKBMDR) is operated by Hong Kong Red Cross Blood Transfusion Service (HKRCBTS) and we are the only registry in Hong Kong for voluntary unrelated bone marrow donors. We help local and overseas patients in need of haematopoietic stem cell (HSC) transplant to find suitable donors. By joining HKBMDR, you may be the one to save life of such patients in any part of the world!

2. 拯救生命的旅程

•登記後您已完成第一步,您 的資料和白血球組織型 (HLA typing) 將被儲存在 我們的資料庫中。當有合適 配對時,我們會與您聯絡!

2. Journey to save a life!

Registration

•You have completed step 1 once you registered, your information and Human Leukocyte Antigen (HLA) typing are stored in HKBMDR's database, and we will contact you if you are a match!

•當您被配對為合適捐贈者時, 我們將安排覆驗,以確認您 是最合適的捐贈者。

Step 2: Verification **Typing**

•Once you are identified as a potential match, we will arrange blood tests to confirm that you are the best match for the patient in need.

第三步: 身體檢查

•我們會安排您接受詳細的身 體檢查,以確保您的身體狀 況適合捐贈。

Step 3: Work-up •You will be undergoing a detailed work-up including physical examination and investigations to ensure that your are healthy for donation.

第四步:

捐贈造血幹 細胞

•您可以透過骨髓採集或周邊 血幹細胞採集進行捐贈。

Step 4: HSC **Donation**

•You would make donation by either Bone Marrow Collection or Peripheral Blood Stem Cell Collection.

第五步: 捐贈後跟進

•香港骨髓捐贈者資料庫會在 捐贈後定期跟進您的情況。

Step 5: Follow-up

•HKBMDR will follow up on your condition regularly after donation.

Educational Pack for Confirmatory Typing and Workup

3. 第一步:登記

誰可以登記成為骨髓捐贈者?我合資格嗎? 登記資格:

- 年齡介平 18 歲至 50 歲
- 身體狀況良好
- 沒有已知傳染病,例如:乙型肝炎、丙型肝 炎、愛滋病

登記時,您須填妥一份健康問卷,以確保您符合 捐贈資格。

如何成為骨髓捐贈者?



您可以親臨各區任何一間捐血站 / 流動捐血隊 / 流動捐血車登記成為 骨髓捐贈者。當您填妥骨髓捐贈者登

記表格,並通過護士的健康查詢後,我們將向您 採集樣本以進行白血球組織型 (HLA) 化驗。

登記後,您的資料將被儲存在我們的資料庫中。 我們將為本地及全球需要接受造血幹細胞移植 的患者進行搜尋及配對。當某特定患者與您配對 為初步脗合時,我們會與您聯絡及安排進一步覆 驗。我們亦有機會因沒有配對成功,而永久不會 與您聯絡。

您只須登記一次,我們將保留您的資料直至您年 齡屆滿60歲,或您主動要求退出為止。

3. Step 1: Registration

Who can join HKBMDR? Am I eligible?

You can join HKBMDR if you are:

- Aged 18-50
- In good health
- Not known to have infectious diseases like hepatitis B, hepatitis C, Human Immunodeficiency Virus (HIV) infection

To make sure you are eligible, you have to complete a health screening questionnaire at HKRCBTS.

How can I join HKBMDR?

You can get started by attending one of the donor centres / mobile donation service / mobile donation vehicles in HKRCBTS. After you have completed a Marrow Donor Registration Form and attended a health enquiry by our nurses, we will collect a sample from you to perform the Human Leukocyte Antigens (HLA) typing.

Once registered, your information will be stored in HKBMDR's database. We will help to search and match donors for patients in any part of the world needed HSC transplantation. If you are found to be a potential match for a specific patient, we will contact you for further testing. However, you may not be contacted for life if no match for a specific patient is found.

Please note that you only have to register once and your information will be kept in the database until you over the age of 60 or you wish to withdraw from our registry.



Educational Pack for Confirmatory Typing and Workup

但某些健康狀況可能會影響您的捐贈資格。如果 您於登記後出現以下健康狀況,請通知我們:

- 傳染病,例如:乙型肝炎、丙型肝炎、愛滋
- 癌症
- 免疫系統或風濕科疾病,例如:強直性脊柱 炎、系統性紅斑狼瘡症、類風濕性關節炎、 硬皮病/CREST 症候群、炎症性腸病或多發 性硬化症
- 內分泌或代謝性疾病,例如:胰島素依賴 型糖尿病
- 心臟或呼吸系統疾病,例如:冠狀動脈疾 病、心肌梗塞或慢性阻塞性肺病
- 神經系統疾病,例如:中風

However, some medical conditions could affect your eligibility to donate. Please inform us if you develop the conditions below after your registration:

- Infectious diseases, such as hepatitis B, hepatitis C or HIV infection
- Cancer
- Autoimmune or rheumatological diseases, such as ankylosing spondylitis, systemic lupus erythematosus, rheumatoid arthritis, scleroderma/ CREST syndrome (calcinosis, Raynaud's phenomenon, esophageal dysfunction, sclerodactyly and telangiectasia), inflammatory bowel disease or multiple sclerosis
- Endocrine or metabolic diseases, such as insulindependent diabetes
- Cardiac or respiratory diseases, such as coronary artery disease, myocardial infarction or chronic obstructive pulmonary disease
- Neurological diseases, such as stroke



骨髓捐贈者登記資格及手續

Bone Marrow Donor Eligibility and Registration

Educational Pack for Confirmatory Typing and Workup

第二步:覆驗

恭喜!您被確定與某特定患者配對為初步脗合。 這將會是一次獨特的旅程,讓您有機會給予患者 重生的機會。



我們的專職聯絡主任將會致電給 您,向您講解有關捐贈造血幹細胞 的資訊和評估您的捐贈資格。歡迎 您向我們提出任何關於捐贈的疑

,直至您了解清楚有關事宜。由於您接受覆驗 後很大機會被選中進行捐贈,因此我們鼓勵您在 決定進行覆驗前,先與您的家人或摯愛商量。您 對患者的承諾很重要,因為患者在接受移植前的 治療將對他/她構成嚴重的後果(包括死亡)。

如果您同意,我們將安排您到捐血站進行覆驗。 屆時您需要填妥一份覆驗同意書及健康問卷,醫 護人員會為您抽取血液樣本以檢驗您的血型、白 血球組織型(HLA)及傳染病檢測,包括:乙型肝 炎病毒、丙型肝炎病毒、愛滋病病毒 (HIV)、T-淋巴細胞病毒(HTLV)、梅毒、巨細胞病毒(CMV) 和水痘帶狀疱疹病毒(VZV)。如有需要,我們會 向您抽取額外的樣本進行測試,以確定您的健康 狀況。

4. Step 2: Verification Typing

Congratulation! You have been identified as a potential match for a specific patient. This will be a unique journey for you to give someone a second chance of life.

HKBMDR will contact you by phone. Your eligibility will be assessed by a trained personnel and we will explain to you about the HSC donation. You have plenty of chance to ask questions until you are clear about the donation. You have a high chance to be chosen to donate, therefore, we encourage you to discuss with your family members or loved ones before making a decision to go for further testing. Your commitment to the patient is important. This is because the intensive chemotherapy preparing the patient for transplant is going to put the patient's life in danger.

If you decide to proceed, we will arrange a blood test with you in one of our donor centres. You are required to complete an informed consent and a health questionnaire. We will obtain blood samples from you to verify your blood group and HLA typing, and to screen for infectious diseases including hepatitis B, hepatitis C, Human Immunodeficiency Virus (HIV), Human T-Lymphotropic Virus (HTLV), Syphilis, Cytomegalovirus (CMV) and Varicella-zoster virus (VZV). Additional testing might be required to determine your health status occasionally.



您的測試報告將被提交予患者所屬的移植中心或相關的資料庫,而您的身份將會以一個捐贈者編號代表。整個捐贈過程中,我們不會披露任何可識別您身份的資料,例如:姓名、身份證號碼或聯絡方法等。倘若您被選中進行捐贈,我們會在三個月內再與您聯絡。

Your test results will be shared with the requesting registry or healthcare professionals taking care of the patient. You will be represented by a registration number and we do not share your identifiable data such as name, HKID or contact information. We will let you know if you are selected for donation in the next 3 months.

以下情況可能有傳播傳染病的風險,或影響您的 捐贈資格:

- 有新的性伴侶
- 與有傳播乙型肝炎、丙型肝炎、愛滋病病毒和其 他傳染病風險的人發生性行為
- 近期曾進行刺體、紋身、針灸或接種疫苗

請於進行覆驗後的3個月內,暫緩全血捐贈及避免懷孕。如果您於未來6個月內有外遊計劃,請盡快告訴我們您的行程和目的地。

Certain activities carry risk of transmitting diseases from you to the patient, or affect your eligibility to donate, such as:

- having a new sexual partner
- having sex with someone who are at risk of transmitting hepatitis B, hepatitis C, HIV and other infectious diseases
- getting a new body piercing, tattoo, acupuncture or vaccinations

Please also avoid donating whole blood or getting pregnant as well within 3 months after you have blood drawn for the testing. If you are intended to travel within 6 months, please let us know your travel plan and destination as soon as possible.

5. 第三步: 身體檢查

您已被確定與特定患者配對為脗合並選為造血幹細胞捐贈者!

在決定捐贈之前,我們的護士會安排一個約兩小時的面談,向您詳細講解造血幹細胞捐贈的資料,包括:捐贈方式、潛在風險、捐贈地點及日期安排等。之後您會有一至兩星期的時間考慮清楚,以作最終決定。如果您同意捐贈,我們的醫護人員會在捐贈前約四星期為您安排身體檢查,以確保您身體健康狀況適合作捐贈。

5. Step 3: Work-up

You are confirmed to be matched with the specific patient and selected to donate HSC!

Prior to your donation, we will contact you for a face-to-face information session which lasts for about 2 hours. During the meeting, we will explain to you about the donation methods and possible risks, location of the donation and the proposed date. You can take 1-2 weeks to make your final decision. If you decide to proceed, a medical checkup will be scheduled around 4 weeks before the donation to ensure you are fit and healthy to donate.



Educational Pack for Confirmatory Typing and Workup

身體檢查當天,我們的血液科專科醫生會與您進 行會診,以了解您的病歷,及評估您的健康狀況, 並會再次講解關於捐贈的方式和風險。我們鼓勵



您當天帶同家人或親人一同出席,並 可以提出任何有關捐贈的疑問。專 科醫生將與您簽署一份同意書,以

確認您明白並同意捐贈。如果您的血液有需要被 保留作研究用途,我們的醫生將會向您作進一步 解釋並與您簽署同意書。

The medical checkup includes a doctor consultation and physical examination. A hematology specialist doctor will evaluate your past medical history and provide more information about the donation and possible risks. You are encouraged to invite your family members or loved ones to attend this session and are free to ask any questions concerning the donation. The doctor will then obtain an informed consent from you. If blood is reserved for research purposes, our doctor will explain to you the purposes and obtain an additional informed consent from you.

您會被安排進行詳細的身體檢查以確保您的健 康狀況適合作捐贈及沒有已知的傳染病,檢查項 目包括:

- 血液測試:
- 直接抗球蛋白試驗
- 血液學測試,包括:全血球計數、紅血球沉降速率、 凝血功能檢查、葡萄糖六磷酸去氫酵素缺乏症 (G6PD)測試、血紅蛋白分析、鐵蛋白
- 生化檢驗,包括:腎臟功能、肝臟功能、甲狀腺功 能和免疫球蛋白組合檢查
- 傳染病,包括:乙型肝炎、丙型肝炎、愛滋病(HIV)、 T-淋巴細胞病毒(HTLV)、梅毒、巨細胞病毒(CMV)
- 心電圖
- 肺部X光
- 小便測試:
 - 糖
 - 蛋白
 - 驗孕測試 (女性捐贈者)

The following investigations will be arranged for you to ensure you are fit for the donation as well as free of transmissible infectious diseases:

- Blood test:
- Direct Antiglobulin Test (DAT)
- Hematology tests, including Complete Blood Count (CBC), clotting profile, Glucose-6-phosphate dehydrogenase deficiency (G6PD), hemoglobin pattern, ferritin
- Biochemistry tests, including kidney, liver, thyroid and immunoglobulin profile.
- Infectious diseases, including hepatitis B, hepatitis C, Human Immuno-deficiency Virus (HIV), Human T-Lymphotropic Virus (HTLV), syphilis, Cytomegalovirus (CMV)
- Electrocardiogram (ECG)
- Chest X-Ray
- Urine test:
 - \triangleright Sugar
 - Protein
 - Pregnancy test (for female donors only)





<u> 骨髓配對及捐贈資訊</u>

Educational Pack for Confirmatory Typing and Workup

身體檢查報告需時兩至三星期,您的報告將會經 過兩名血液科專科醫生的評核並確定您的捐贈 資格。如有需要進行進一步測試或覆驗,我們的 護士將聯絡您以作安排。

It will take 2-3 weeks for the final clearance. HKBMDR will arrange two separate hematology specialist doctors to review your results and determine eligibility. additional your investigations are required for the decision, our nurses will contact you for follow-up.

6. 第四步: 捐贈造血幹細胞

當您通過身體檢查後,您將被安排到醫院管理局 轄下的採集中心進行骨髓(BM)或周邊血幹細胞 (PBSC) 捐贈。

Step 4: HSC Donation

Once you are cleared for donation, you can proceed to donate HSC via either Bone Marrow donation (BM) or Peripheral Blood Stem Cell (PBSC) donation. The procedure will be taken place in a collection centre of a public hospital.

捐贈方法一:骨髓採集

骨髓捐贈是一項在全身麻醉下進 行的外科手術。在入院前您先要 接受麻醉科醫生的評估,然後會 安排您在平日入院,於翌日的早 上進行捐贈,通常在捐贈後的-天您便可以出院,住院總日數-般為三天。



您需要在捐贈前八至十小時開始禁止飲食。捐贈 當天,醫護人員會將您送到手術室。麻醉科醫生 會先向您進行靜脈注射麻醉藥物,並放置氣管導 管以協助您在手術過程中呼吸。

Donation Method 1: Bone Marrow (BM) Harvest

Bone Marrow Donation (BM) is a surgical procedure performed under general anesthesia. You will be assessed by an anesthetist before hospital admission. Hospital admission will be arranged on a weekday and the donation will be done in the next morning. You will be expected to discharge one day after the harvest. The total length of hospital stay is 3 days normally.

You are required to keep fast 8-10 hours before the donation. Healthcare worker will transfer you to the operating room where an anesthetist will give you anaesthetic medication intravenously and put a breathing tube in your throat to assist your breathing during the procedure.



<u> 骨髓配對及捐贈資訊</u>

Educational Pack for Confirmatory Typing and Workup

全身麻醉後,醫生會使用特製針筒於您兩邊的盤 骨位置抽取骨髓血並儲存於一個專用收集袋中。 一般而言,醫生會抽取約八百至一千毫升的骨髓 血(少於一般人身體內的總造血幹細胞量的百分 之三(3%))。如果患者體重較輕,需要抽取的骨髓 血則較少。捐贈完成後,醫生會在您的傷口部位 進行加壓包紮。由於傷口很小,因此不需要縫合。 手術結束時,麻醉師會為您進行逆轉麻醉,讓您 慢慢甦醒及回復知覺。整個捐贈過程大約需要一 小時。



手術後,您會被安排到復甦室進行進一步監測。 當醫護人員確認您的情況穩定,便會安排您回到 病房,回到病房時,您需要臥床休息。捐贈後, 您可能會感到頭暈、傷口部位疼痛或觸痛。您可 以服用止痛藥,以消除不適。當天下午至黃昏時, 您可以恢復日常活動,包括走路及飲食。如果您 有任何不適或疑慮,請立即通知病房的醫護人 員。一般而言,於捐贈後翌日便會安排您出院。 您的身體會於短時間內逐漸地自行補充所捐出 的造血幹細胞。



After putting you under general anesthesia, the doctors will insert special needles into the iliac crest cavity of both sides of your pelvic bone to collect marrow blood, then the marrow blood will be collected into a special bag. Normally, 800-1000ml of marrow blood (less than 3% of your body's total HSC) is enough. If your intended patient is lighter, the volume of marrow blood to be drawn will be less. When the donation is done, doctors will apply pressure dressing to your wounds. Since the wounds are typically small, no stitching is required. At the end of the procedure, an anesthetist will withhold the anaesthetic medication and allowing you to wake up and regain consciousness gradually. The donation process usually takes around one hour.

You will be transferred to the recovery room for close monitoring after the procedure, when your condition is confirmed to be stable by healthcare



professionals, you will be transferred back to your room. You are required to bed rest when you return to your room. You may feel dizzy after donation and the puncture sites may be sore and tender. Pain medication is usually effective in relieving the discomfort. Later in the day, you can walk, eat and drink again. Do not hesitate to report any discomfort or concerns you are experiencing to the staff in the ward. In a normal situation, you are expected to be discharged the day after donation. Your body could gradually replenish the donated HSC within a short period of time.

Educational Pack for Confirmatory Typing and Workup

骨髓捐贈的風險和不良反應

在手術室進行骨髓捐贈的風險主要與全身麻醉 有關的風險。現時的麻醉技術比以往安全,您的 麻醉科醫生會採取一切預防措施以減低事故發 生的機會。全身麻醉有機會引起一些不良反應, 例如噁心、嘔吐、嗜睡、顫抖、頭暈或甦醒期躁 動。這些不良反應通常是輕微和短暫性的,醫護 人員亦會為可能出現不良反應的您作好準備。對 於健康人士而言,出現嚴重或致命併發症的機會 率是極低。

捐贈後您會感到疲倦,傷口部位可能會出現瘀 腫,亦可能持續數天感到下背部疼痛和僵硬。偶 爾會出現傷口感染。在極少的情況下,偶有引致 針刺位置周圍的骨骼、神經或肌肉損傷。如果您 有任何不適或疑慮,請通知我們的醫護人員,我 們將為您作跟進和轉介合適的治療。

自身揭加

因應捐贈者的身體狀況和預計捐贈骨髓血之份 量,部份捐贈者或需在手術前進行自身捐血。這 程序會在捐贈骨髓前七至十四天於香港紅十字 會輸血服務中心總部進行。

Risks and adverse effects associated with Bone Marrow Donation

The risks of donating bone marrow, which is carried out in the operating room, are mainly those associated with general anesthesia. Anesthesia is safer today than it has ever been, and your anesthetist will take every precaution to prevent accidents from occurring. Mild adverse effects may happen, such as nausea, vomiting, drowsiness, shivering, dizziness, or agitation upon awakening. These can be somewhat distressing, but are rarely dangerous, and our staff will do their best to anticipate these side effects, prepare you for their possible occurrence and prevent those that are avoidable. In a healthy person, the chance of a serious life threatening complication is extremely low.

It is normal for you to feel fatigue immediately after donation. Bruises may appear at the puncture sites, and you may feel pain and stiffness in the lower back for a few days. Infection may rarely occur at the sites. In very rare cases, damage may be caused to the surrounding bones, nerves or muscles. Please inform our staff if you experience any discomfort or concern and we will help to refer you for suitable treatment and follow-up.

Autologous blood donation

Subjected to the physical condition of donors and the estimated amount of marrow blood to be donated. some donors may be requested to donate a unit of blood for him/herself before donating the bone marrow. This procedure will be conducted 7 to 14 days prior to the bone marrow donation at the donor centre of HKRCBTS headquarter.

Educational Pack for Confirmatory Typing and Workup

復原

在捐贈後的翌日,醫生便會安排您出院,並給您 處方一些止痛藥和鐵質補充劑。您的傷口部位會 被蓋上無菌敷料,除非有任何滲漏,否則不需要 更換。過幾天後可以移除敷料。如果傷口部位出 現紅腫、觸痛、劇烈疼痛或持續滲血的情況,請 通知我們的護士作進一步跟進。

我們會於捐贈後向您發出病假證明書,並建議您 在家休息一星期。休息期間,您應盡量減少活動 並多加休息。請謹記完成整個鐵質補充療程, 並多吃含豐富維他命 C 的食物,可加強鐵質的 吸收。鐵質補充劑有機會導致腸胃不適及便 秘,於日常飲食中增加纖維及水份的攝取量, 有助改善有關情況。如果傷口位置出現疼痛, 我們建議您服用止痛藥。由於復原速度因人而 異,因此我們建議捐贈者應於捐贈後兩至三星 期內,盡量避免進行劇烈運動,並與我們保持 聯絡以了解您復原的進度。

Recovery

You will be discharged next day following the donation. Pain medication and iron supplements will be prescribed upon discharge. Your puncture sites will be covered with sterile dressing which no need to be replaced unless oozing is noted. The dressing may be removed completely after a few days. If you experience any unexpected redness, tenderness, severe pain or continuous oozing from your puncture sites, please contact our staff for further management.

After donation, you are advised to take a week off from work and rest at home, sick leave certificate will be issued to you. Within that week, you should limit your activities and stay rest. Please remember to finish the whole course of iron supplements. To help increasing the iron absorption, you are also advised to take more vitamin c- rich food. Sometimes. iron supplements may cause Gastrointestinal (GI) upset and constipation, increasing fluid and dietary fiber intake may ease the conditions. You are advised to take the pain medication if you experience pain at the puncture site. Please avoid sport or intensive activities for 2-3 weeks after donation although exact period leading to full recovery varies from donor to donor. Do keep in touch with our staff for the progress.



骨髓捐贈 **Bone Marrow Donation**

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捐贈方法二:周邊血幹細胞捐贈

周邊血幹細胞捐贈(PBSC)是一項非手術程序,透 過血液分離機收集造血幹細胞。您需在捐贈前三 至四天接受白血球生長激素 (G-CSF) 注射,目 的是將骨髓內之造血幹細胞動員至周邊血液才 進行收集。

白血球生長激素(G-CSF)



白血球生長激素(G-CSF)是一種短 效藥物,用於增加周邊血液中造血 幹細胞的數量。從一九九零年代初 以來, G-CSF 已被用於健康捐贈者 身上。您將被安排在捐贈前三至四天

起,每天到捐血站於手臂或腹部的皮下位置注射 G-CSF。在捐贈前一天,我們會為您抽取血液樣 本以檢驗造血幹細胞數量。

捐贈流程

捐贈當天,您需於早上到達採集中心。中心會使 用一部血液分離機進行採集。捐贈時,醫護人員 會將無菌針管置入您的血管,您的血液將經由針 管,抽取至血液分離機中。血液分離機會將血液 中的造血幹細胞分離,並採集到特製的收集袋 中,而其餘的血液成份會經由另一針管輸回到您 的體內。這個程序會重複並持續大約四至六小 時。過程中抽取的造血幹細胞份量一般為二百五 十至四百毫升,少於一般人身體內的總造血幹細

胞量的百分之三(3%),您的 身體會於短時間內自行補充 捐贈出的造血幹細胞。



Donation Method 2: Peripheral Blood Stem Cell Donation

Peripheral blood stem cell (PBSC) donation is a nonsurgical procedure to collect HSC from your bloodstream. You will have to receive Granulocyte Colony Stimulating Factor (G-CSF) injections for 3-4 days prior to donation, for the purpose of mobilizing HSC from the bone marrow into the circulating peripheral blood for the collection.

Granulocyte Colony Stimulating Factor (G-CSF)

G-CSF is a short acting mobilizing agent used to increase the number of HSC in your bloodstream. It has been used in healthy donors since early 1990s. You will receive G-CSF injection in your arms or abdomen subcutaneously for 3 to 4 consecutive days prior to donation. The injection could be given in any of our donor centres. One day before donation, a blood sample will be drawn to check the number of HSC in your bloodstream.

Collection Process

You will have to arrive at the collection centre in the early morning on the scheduled date. The collection will be proceeded with an apheresis machine. During the procedure, your blood will be drawn through a sterile needle on your arm and passed through the machine. The machine will separate your HSC from your blood. The HSC will be collected in a bag and the remaining blood will be returned to you through another needle. This process repeats and lasts for around 4 to 6 hours. The final HSC product is typically 250-400ml, which contains less than 3% of your body's total HSC, and your body could replenish the donated HSC within a short period of time.



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捐贈完成後,捐出的造血幹細胞將立刻送往仕驗 室進行處理和計算細胞數量,並會安排您在同日 出院。大部份捐贈者在一次採集中已經能夠成功 採集到足夠的造血幹細胞數量,但亦有部份捐贈 者,因為採集的造血幹細胞數量不足,而需要在 翌日進行第二次的採集。

在極少的情況下,捐贈者注射白血球生長激素 (G-CSF)後,未能將造血幹細胞動員到周邊血液 中。在這情況下,您可能會被邀請使用其他捐贈 方法,即是進行骨髓捐贈。我們會在捐贈前先與 您討論這個後備方案,並取得您同意才進行捐 贈。

放置中央靜脈導管

我們的醫護人員會在面談期間評估您的靜脈血 管狀況。如果您的手臂靜脈血管被評估為不合 適,那麼在捐贈前需要在您的頸靜脈放置一條雙 腔導管,以確保捐贈期間有穩定暢順的血流。我 們會先與您討論放置頸靜脈導管有關的資訊和 風險,並與您簽署同意書。您將在捐贈前一天入 院,由放射科醫生在超聲波的引導下放置導管。

周邊血幹細胞捐贈的風險和不良反應

白血球生長激素(G-CSF)注射後,常見的副作用 包括輕微骨痛、肌肉疼痛、頭痛或類似感冒等輕 微症狀,症狀通常在最後一次注射後一至兩天消 失。醫生會為您處方止痛藥,而護士會在注射期 間密切監測您的情況。

When the collection is completed, the HSC product will be sent to the laboratory immediately for cell count and processing before use. You will be expected to be discharged on the same day of donation. The majority of donors would achieve the intended HSC dose in one-day collection. Some donors may have to undergo a second day collection if the intended HSC dose is not reached.

Occasionally, HSC is not satisfactorily mobilized to the bloodstream after G-CSF, you may be invited to use the alternative method of donation, which means bone marrow donation. This backup option will be discussed with you during the consent process prior to donation.

Central Venous Catheter Placement

Staff from HKBMDR will assess your veins during the information session. If you do not have suitable arm veins, a double lumen catheter may be needed to insert into your neck vein to ensure optimal blood flow during donation. Information about the possible risks will be discussed with you. A separate informed consent will be obtained from you. You will be admitted to the hospital 1 day prior to donation for the catheter insertion under ultrasound guidance by a radiologist.

Risks and adverse effects associated with PBSC **Donation**

The more frequent side effects of G-CSF injection are mild bone pain, muscle pain, headaches or other flu-like symptoms, which usually disappear 1-2 days after the last injection. Pain medication will be given to you to relieve the discomfort; your case nurse will closely monitor your condition.



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G-CSF 已被全球許多衛生機關核准,於癌症患者 G-CSF has been approved by many health 及造血幹細胞捐贈者身上常規使用;而接受 G- authorities around the world for regular use in cancer CSF 注射後的長期影響,目前還沒有定論,所以 patients and healthy donors, its long term effects in 在捐贈後我們亦會定期跟進您的身體狀況。

一般而言,經血液分離機採集造血幹細胞的過程 是安全的。部份捐贈者可能因短暫的低血鈣而引 致嘴邊、手指、腳趾有輕微刺痛或肌肉抽筋狀況, 透過調節捐贈的速度、服用含鈣飲品或鈣質補充 劑可舒緩這些徵狀。

捐贈過程中亦可能出現因血壓下降而導致的頭 量和昏厥。

捐贈後,入針部位可能會出現疼痛、瘀腫、發炎、 **咸染或皮膚過敏。這些不良反應通常是輕微和短** 暫性的。

復原

完成捐贈後,採集中心的護士會密切監測您的情 況至少 30 分鐘。當您的身體狀況穩定便可以出 院回家。

捐贈後,您手臂上的入針位置可能會出現瘀腫或 肌肉抽筋,您或會感到疲倦。大部份捐贈者會在 一至兩天內完全康復,因此我們會向您發出病假 證明書,並建議您在家休息兩天。如果您的手臂 持續出現疼痛或麻痺,或有任何疑問或不適,請 聯絡我們作進一步跟進。

healthy donors remains immature, therefore we offer to arrange follow-up with you regularly after the donation.

Apheresis procedure is generally safe. Some donors may experience tingling around mouth, fingers and toes, and mild muscle cramps during the donation due to lowering of blood calcium. These symptoms can easily be relieved by slowing down the donation process and taking calcium supplement or drinks.

Dizziness and fainting due to blood pressure drop may occur during the donation.

Some donors may experience pain, bruise, inflammation, infection or skin allergy over the needle puncture site after the donation. These events are usually short-term and rarely dangerous.

Recovery

Nurse at the collection centre will monitor you for at least 30 minutes after you have completed the donation. You will be discharged if you are well.

You may have bruises or muscle cramp at the needle puncture sites on your arms or feeling tired after PBSC donation. As most donors recover completely within 1 to 2 days, you are advised to take 2 days off from work and rest at home, sick leave certificate to you. If you encounter persistent pain numbness over your arms, or any other concern or complication, please contact our staff for further assessment.



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所有經骨髓或周邊血幹細胞捐贈所抽取出來的 造血幹細胞,只會捐贈給特定患者作移植用途, 如果因為病人情況有變而最終未能進行移植,我 們將會通知您。

For both BM and PBSC donation, the product collected will be for intended patient use only. In case unforeseeable event occurs and the product is not infused eventually, you will be informed.



周邊血幹細胞捐贈

Peripheral Blood Stem Cell Donation

7. 第五步:捐贈後跟進

我們會在捐贈後的七十二小時內聯絡您作第一 次跟進。捐贈後的一星期(周邊血幹細胞捐贈 者)或一個月(骨髓捐贈者)後,我們會為您安 排一次抽血覆驗。之後便會安排每年跟進一次, 直至捐贈後十年。期間如果您有任何嚴重的健 康問題,請通知我們的工作人員。

再次捐贈

捐贈後,我們會將您預留一段時間予同一位患 者。在這段期間,如果患者出現復發或併發症, 我們有機會聯絡您再次捐贈造血幹細胞,或淋巴 細胞捐贈(白血球的其中一種,不需要白血球生長 激素(G-CSF)注射,只需捐贈血液成份中的淋巴 細胞)。再次捐贈的風險和不良反應與第一次相 似。如果需要再次捐贈,我們會再邀請您作講解 並再次與您簽署同意書。

Step 5: Follow-up

Staff from HKBMDR will make a first review of your condition within 72 hours of donation. Then, we will arrange a follow-up blood check 1 week (for PBSC donors), or 1 month (for BM donors) following your donation. After that, an annual follow-up will be arranged till 10 years of donation. If you have any significant health issues, please inform our staff.

Subsequent Donation

You will be reserved for a period for the same patient. During this period, you may be contacted for a subsequent donation if your patient relapses or develops unexpected post-transplant complications. It may be a HSC donation as you did before or lymphocytes donation (one kind of white blood cell) by apheresis without the need of G-CSF. The risks and adverse effects of a subsequent donation are similar to those of the first one. If subsequent donation is needed, you will be invited for discussion and obtain informed consent again.



Educational Pack for Confirmatory Typing and Workup

8. FAQs

病人會知道我的身份嗎?

香港骨髓捐贈者資料庫採取嚴格的保護措施,保 障捐贈者和患者雙方身份的隱私。您的身份將會 以一個捐贈者編號代表。在整個捐贈過程中, 我們不會披露任可識別您身份的資料,例如: 姓名、身份證號碼或聯絡方法等。同樣地,患 者的資料也將會被保密。

我可以說"不"嗎?

您有權隨時退出捐贈計劃,但我們強烈建議您應 避免在患者開始了接受移植前的治療時才退出 捐贈,因為若延至其時才選擇退出,將對患者構 成嚴重後果(包括死亡)。

誰決定我的捐贈方式?

移植中心醫生會因應患者的情況,提議捐贈方 式,但您有權選擇捐贈造血幹細胞的方法。我們 的醫護人員亦會因應您的身體健康狀況作出建 議。

誰支付與捐贈相關的費用?

香港骨髓捐贈者資料庫會負責支付與捐贈相關 的檢測費、注射費及住院費用。我們會償付您所 有預支與捐贈相關的支出。

8. FAQs

Will the patient know my identity?

HKBMDR maintains strict privacy protection to both donors and patients. Your identity will be represented by a registration number and we do not share your identifiable data such as name, HKID or contact information along the whole process of donation. Likewise, similar data of patients will not be disclosed.

Can I Say "No"?

You have the right to withdraw from the registry anytime. Nonetheless, you are highly advised to make the decision before an intended patient undergoing intensive chemotherapy for This transplant. is intensive because the chemotherapy is going to put the patient's life in danger.

Who decides my donation method?

The transplant centre doctor taking care of the patient will prioritize the donation method to maximize the transplant outcome of the patient. However, you have the final right to choose the donation method which is not contraindicated to your health. HKBMDR healthcare staff will also provide advices on the donation method according to your health condition.

Who pays for the donation?

HKBMDR will be responsible for the testing fee, injection fee and hospital costs related to the donation. All your out-of-pocket costs related to the donation will be reimbursed.



骨髓捐贈配對及捐贈資訊

Educational Pack for Confirmatory Typing and Work up

捐贈後我可以與病人會面嗎?

每個國家或地區對於捐贈者和受髓者之間的聯 Every country has different policy about direct 絡都有不同的政策。在香港,捐贈後兩年內,您 和患者可以透過HKBMDR進行匿名的書信來 往。捐贈兩年之後,如果您和受髓者都希望見 面,我們在獲得雙方的同意後,便會因應情況 而安排見面。

我的捐贈會有保險保障嗎?

捐贈者在捐贈後會有一年意外事故保險,保障包 括因意外受傷所需支付的醫療費用、因意外引致 永久性傷殘和死亡;但不包括因工作遭受事故的 傷害。如發生與捐贈有關的不良事故,捐贈者將 由香港骨髓捐贈者資料庫及醫院管理局作跟進。

Will I meet the patient after donation?

contact between donors and recipients. Within two years of donation, anonymous communication through HKBMDR between you and the patient residing in Hong Kong is possible. After two years, if both you and the recipient wish to meet each other, HKBMDR is able to arrange meeting after obtaining consents from both of you depending on the situation.

Will there be any insurance coverage for my donation?

Donor is covered in the event of accident by insurance for one year following the donation including medical expenses, disablement and death; but not occupation-related injuries. In case of adverse event related to donation, donor will be followed up by HKBMDR and Hospital Authority.

香港骨髓捐贈者資料庫 HONG KONG BONE MARROW DONOR REGISTRY



明 Privacy Policy Statement

私隱聲明

Privacy Policy Statement

1. 政策聲明

我們承諾遵守《個人資料(私隱)條例》 有關個人資料管理的規定,及其他可 應用的海外法規,以保障我們所持有 的個人資料的私隱、保密及安全。我 們同樣致力確保我們所有的員工和合 作夥伴都履行這些義務。

2. 機構背景

香港紅十字會輸血服務中心由法定機 構醫院管理局(「醫管局」)管轄,並 獲香港紅十字會指定營運[香港骨髓 捐贈者資料庫],為本地及全球需要接 受造血幹細胞移植的患者搜尋及配對 合適的無血緣骨髓捐贈者。

在本聲明中,「我們」是指香港紅十字 會輸血服務中心。

3. 我們會收集甚麼個人資料以及何時收 3 集?

我們可能會在不同的情況下收集個人 資料,包括:

Policy statement 1.

We are committed to protecting the privacy, confidentiality and security of the personal information we hold by complying with the requirements of Personal Data (Privacy) Ordinance ("PDPO") and other applicable overseas statutes with respect to the management of personal information. We are equally committed to ensuring that all our employees and partners uphold these obligations.

2. Who are we?

Hong Kong Red Cross Blood Transfusion Service ("BTS") is managed by a statutory body, the Hospital Authority ("HA"), and appointed by Hong Kong Red Cross ("HKRC") to operate the Hong Kong Bone Marrow Donor Registry ("HKBMD Registry") in providing Human Leukocyte Antigen ("HLA") typing for bone marrow donors ("donors") and donormatching services for patients requiring unrelated haematopoietic cell stem transplantation ("recipients").

In this Statement, "we", "us" and "our" refer to BTS.

What information and when do we collect?

We may collect personal information in different contexts, including:

- 3.1 當閣下登記成為骨髓捐贈者時,我們 3.1 會收集閣下的姓名、香港身份證號碼、 聯絡資料、出生日期、性別、種族、族 裔、捐血紀錄、捐血者編號和病歷,醫 護人員會抽取少量血液樣本作白血球 組織型檢驗;
 - when you register as a donor, we collect your name, Hong Kong ID number, contact information, date of birth, gender, race, ethnicity, blood donation history, blood donor ID, health history, and a sample for HLA typing;
- 3.2 當閣下被選定捐贈給某特定患者,我 3.2 們會查詢更多關於閣下的健康狀況和 生活習慣,例如:曾否服用非處方藥 物、性生活、因性取向而可能經輸血傳 播傳染病的風險等。醫護人員會抽取 閣下的血液樣本以檢驗閣下的白血球 組織型、血型和傳染病檢測;
- when you are selected for a specific recipient, we collect more information about your health, behavioral information such as the use of recreational drugs, sex life, sexual orientation which may affect the risk of transfusion transmitted infection, and some blood for HLA confirmatory typing, blood group and infectious markers screening;
- 3.3 當醫院轉介閣下為受贈者時,我們會 收集閣下的姓名、出生日期、病歷、白 血球組織型報告、病狀和治療方案;
- 3.3 when you are referred to us as a recipient, we collect your name, date of birth, health history, HLA typing result, disease status and treatment plan;
- 3.4 在移植後,我們均會收集捐贈者和受 贈者的健康狀況資料以作跟進;
- we collect follow-up information about your health when a donation is made as a donor or a transplant is made as a recipient;
- 3.5 當閣下參加我們的活動,例如:捐贈 者嘉許禮或宣傳活動時,我們可能會 收集閣下的姓名、聯絡資料、相片和影 片;我們還可能會透過採訪,搜集閣下 所分享的故事和經歷;
- 3.5 when you participate in our activities such as donor ceremonies or promotion events, we may collect your name, contact information, photos and footage; we may also collect information about your story, including your information and experience, by conducting interviews with you;
- 3.6 當閣下參與我們的義工服務或向我們 3.6 作出捐款時,我們會收集閣下的姓名、 聯絡資料和其他相關資料;
 - when you participate in our volunteer work or provide a financial donation to us, we collect your name, contact information and other relevant information:

- 3.7 當閣下向我們申請工作或實習時,我 3.7 們會收集閣下的個人背景資料、聯絡 資料、工作經驗、學歷和其他相關資 料;
- 3.8 當閣下向我們提出意見或要求我們與 您聯絡時,我們會收集閣下的姓名、聯 絡資料和其他相關資料。
- 我們如何使用閣下的個人資料 4.

閣下所提供的個人資料會用於下列項 目:

4.1 為本地及全球需要接受造血幹細胞移 植的患者提供白血球組織型搜尋及配 對服務:

> 由捐贈者及患者所提供的個人資料, 會於為本地及全球造血幹細胞移植的 過程中使用,包括造血幹細胞移植的 搜尋及配對服務、安全及成效評估、與 造血幹細胞捐贈有關的科學研究、員 工培訓、質量管理、評估及規劃服 務、服務認證、內部審核、處理賬單及 繳費事宜、保險及財務事宜。

4.2 宣傳:

- 就[我們的社交推廣活動]所收集的個 人資料會用作組織和管理捐贈相關的 活動,以及宣傳和推廣我們的工作及 服務;
- 在我們網站上所收集的個人資料會用 於了解瀏覽者的習慣和瀏覽量、改善 閣下的瀏覽體驗、找出與電腦系統相 關的問題,以及其他統計和改善服務 F .

- when you apply for a job or internship with us, we collect your personal particulars, contact information, job experience, qualifications and other relevant information; and
- when you provide feedback to us or request us to contact you, we collect your name, information and other relevant information.

How do we use your information?

Your information will be used for the purposes set out below.

Donor-matching services for patients requiring 4.1 haematopoietic stem cell transplantation:

Information collected from donors and recipients is used for the procedure of haematopoietic stem cell transplantation including the search and match; safety and outcome evaluation of the procedure; scientific research relating to haematopoietic stem cell transplantation; staff training; quality control; service planning; research; accreditation; audits; administer payments and billings; and insurance and financing processes.

Publicity: 4.2

- Information collected in relation to our [social and/or promotional] events is used to organize and administer those events and to publicize and promote our work and services;
- Information collected on our website is used to obtain an overall view of visitor habits and volumes to our website, improve your browsing experience with us and to diagnose problems with or concerning computer systems and for other statistics and service improvement purposes.

4.3 處理意見:

就閣下的訴求所收集的個人資料會用 作回應及處理閣下的意見。

4.4 處理捐款:

就閣下捐款所收集的個人資料會用作 管理捐款。

4.5 招聘工作或義工服務:

就閣下工作申請所收集的個人資料會 用於評估閣下的申請,如成功申請, 則會用作處理您的聘請或義工工作。

4.6 法律和監管責任:

所收集的個人資料可能會用於遵守法 律、監管要求或法院命令。

當我們使用閣下一些較敏感的個人資料,例如有關閣下的健康、種族、族裔、 白血球組織型等資料時,我們會使用 保密措施,例如假名或匿名資料(如適用)。

如閣下的個人資料須用於任何其他目的,我們會先徵求閣下的同意。

5. 我們向誰披露閣下的個人資料?

就以上第 4 條所列目的,我們有可能 向以下人士(可能位於香港或海外)披 露閣下的個人資料:

4.3 Managing feedback:

Information collected from your request is used to respond to and manage your feedback.

4.4 Processing financial donation:

Information collected from your financial donation is used to administer and process the donation.

4.5 Job application or volunteering:

Information collected from your job application is used for the purposes of assessing your application and, if successful, administering your employment or volunteer role.

4.6 Legal and regulatory obligations:

We may also use your information to comply with applicable legal or regulatory requirements or court orders as necessary.

When using your sensitive personal data such as information about your health, race, ethnicity, tissue type, we will implement appropriate security measures such as pseudonymising or anonymising information (where applicable).

We will obtain your consent before using your personal data for any other purposes.

5. To whom do we disclose your information?

Your information may be disclosed to the following persons (who may be located in Hong Kong or overseas) for the purposes set out in section 4 above.

5.1 一般:

閣下的個人資料有可能會披露給協助 我們進行第 4 條所列目的的第三方 服務提供者(如行政、資訊科技、收費 服務和保險服務),亦有可能披露給有 需要知道該等個人資料的專業顧問包 括審核員和律師。

5.2 為本地及全球需要接受造血幹細胞移 植的患者提供白血球組織型搜尋及配 對服務的機構:

閣下的個人資料有可能會披露給捐贈 者和受贈者的授權代表、世界骨髓捐 贈者協會及其他國家的骨髓捐贈者資 料庫。

如受贈者已接受移植,閣下的一般健 康狀況資料可能會披露給捐贈者(或 捐贈者的授權代表)。

5.3 宣傳:

有關閣下的經歷的相片和影片,有 可能會被發佈在我們的網站或社交媒 體或大眾媒體上。

5.4 處理賬單及繳費:

閣下的個人資料有可能會披露給法定 機構的財務部門,如撒瑪利亞基金和 其他用於處理任何繳款或收款項目的 金融機構。

5.5 保險:

捐贈者的個人資料有可能會披露給辦 理相關保險的保險公司。

5.1 General:

Your information may be disclosed to third party service providers who provide services to us (such as administrative, information technology, payment services and insurance services) which help us carry out the purposes set out in section 4 above, and to professional advisers such as auditors and lawyers on a need-to-know basis.

Donor-matching and donation services for patients requiring haematopoietic stem cell transplantation: Your information may be disclosed to authorized representatives of donors or recipients, the World Marrow Donor Association and other bone marrow donor registries.

If you have received a transplant, your general health information may be disclosed to the donor [or the donor's representatives].

5.3 Publicity:

Photos or footage with you included or your story may be posted on our website or social media or in mass media.

5.4 Processing payments:

Your information may be disclosed to financial departments of statutory bodies such as the Samaritan Fund and other financial institutions for the processing of any monies receivable or payable.

5.5 Insurance:

If you are a donor, your information may be disclosed to insurance companies for the processing of relevant insurance.

5.6 相關機構:

閣下的個人資料有可能會披露給醫院 管理局所管轄的機構、香港紅十字會、 香港骨髓捐贈基金及其各自的第三方 服務提供者。

5.7 法律和監管責任:

閣下的個人資料有可能會披露給具法 律效力或規例要求的相關政府部門、 監管機構、法定委員會或執法機構。

在閣下同意的情況下,閣下的個人資 料也可能會披露給任何第三方。

6. 我們如何保障閣下的個人資料?

閣下的個人資料是受到保護和保密處 理。我們已實施適當的技術和有系統 性的安全措施,以保障閣下的個人資 料免受意外遺失或非法處理,包括有 關設備、系統、防火牆以及加密信息 存儲的實體和邏輯安全性存取。我們 會有專職的資訊科技及資料管理團 隊,包括資料控制員。我們會確保閣 下的個人資料是按照 《個人資料(私 隱)條例》和其他可應用的海外法規以 作管理。但是,我們不能保證通過互 聯網傳輸的數據(包括電子郵件或資 訊存儲技術)是安全的,一些已超出 我們控制範圍以外的未經授權或非故 意存取,我們不會承擔任何責任或義 務。

Related entities: 5.6

Your information may be disclosed to entities controlled by the HA, the HKRC, the Hong Kong Marrow Match Foundation and their respective third party service providers.

5.7 Legal and regulatory obligations:

Your information may be disclosed to relevant government departments, regulators, statutory boards or authorities or law enforcement agencies to comply with applicable legal or regulatory requirements.

Your information may also be disclosed to any other party with your consent.

How do we protect your information? 6.

information is protected and treated confidentially. We have implemented appropriate technical and organizational security measures to protect your information against accidental loss or unlawful processing, including measures with respect to physical and logical (access) security on equipment and systems, firewalls and safe (encrypted) storage of information including the formation of a designated information technology and information management team including a data protection officer. We make sure that we manage your information in accordance with the requirements of PDPO and other applicable overseas statutes. However, no data transmission over the Internet, including emails, or information storage technology can be guaranteed to be secure, and we shall not be liable or held responsible for unauthorised or unintended access which is reasonably beyond our control.

7. 我們會將閣下的個人資料保留多長時

閣下的個人資料將被保留以貫徹在指 明目的及適用的情況下被使用,並符 合法律和監管規定。在完成每個捐贈 階段的合理期限後,我們將刪除或移 除能夠識別閣下的個人資料。而閣下 用於宣傳上,已發佈在社交媒體或大 眾媒體的相片、影片、捐贈/受贈經歷 等,則由媒體機構的保留政策予以保 留,而非我們控制範圍以內。

8. 如何查閱和更改個人資料?

如果你希望根據《個人資料(私隱)條 例》要求查閱/改正香港紅十字會輸 血服務中心持有你的個人資料,請依 本文末段資料在辦公時間內與我們的 資料控制員聯絡。

9. 如何就本私隱聲明提出問題?

如閣下對此聲明有任何查詢或意見, 請依本文末段資料在辦公時間內與我 們的資料控制員聯絡。

10. 更新私隱聲明

此聲明於二零二二年十二月修訂。

我們將會不定期審查和更新本聲明。 本聲明的更新將會發佈在我們網站 上,如在收集和處理閣下的個人資料 方面有重要變更,我們將會在網站上 清楚列明或直接與閣下聯絡。

How long do we retain your information?

Your information will be kept to assure the defined purposes and if applicable, to fulfil the applicable legal and regulatory requirements. We will remove or de-identify your information after a reasonable period of completion of each defined purpose. Your information such as photos, footage, stories for publicity purposes passed to the social media or mass media will be retained by them according to their retention policies which are beyond our control.

How do you access or correct your information?

You have the right under the PDPO to seek access to and correction of the personal information we hold about you. Please contact our data controller via the information at the bottom of this Statement during BTS's office hours.

How can you ask questions about this Privacy **Policy Statement?**

If you still have any questions, comments or concerns after reading this Statement, please contact our data controller via the information at the bottom of the Statement during BTS's office hours.

10. Changes to this Privacy Policy Statement

This Statement was updated in [December] 2022.

We will review and update this Statement from time to time. Updates to this Statement will be posted on our BTS website and, if any significant changes are made in respect to the collection and processing of your information, we will make this clear on our BTS website or by contacting you directly.

11. 聯絡我們:

如閣下對此聲明有任何查詢或意見, 請在辦公時間內與我們的資料控制員 聯絡:

熱線: 2710-1206 傳真: 2780-0021

電郵: hkbmdr.coordinators@ha.org.hk

地址: 九龍京士柏道 15 號

11. Contact [us]:

If you have any questions, comments or concerns after reading this Statement, please contact our data controller during BTS's office hours at:

Hotline: 2710-1206 Fax: 2780-0021

Email: hkbmdr.coordinators@ha.org.hk Address: 15 King's Park Rise, Kowloon

此中文聲明條款為英文版本譯本,如中、 英文兩個版本有任何抵觸或不相符之處, 應以英文版本為準。

This Statement has been translated into Chinese. If there is any inconsistency or ambiguity between the English version and the Chinese version, the English version shall prevail.



香港骨髓捐贈者資料



HONG KONG BONE MARROW DONOR REGISTRY

個人資料收集聲明 - 捐贈者

Personal Information Collection Statement - Donors

個人資料收集聲明 - 捐贈者

Personal Information Collection Statement - Donors

1. 機構背景

香港紅十字會輸血服務中心由法定機 構醫院管理局(「醫管局」)管轄,並 獲香港紅十字會指定營運[香港骨髓 捐贈者資料庫],為需要接受造血幹細 胞移植的患者搜尋及配對合適的無血 緣骨髓捐贈者。

在本聲明中,「我們」是指香港紅十字 會輸血服務中心。

2. 我們會收集哪些個人資料?

當閣下登記成為骨髓捐贈者時,我們 會收集閣下的姓名、香港身份證號碼、 聯絡資料、出生日期、性別、種族、捐 血紀錄、捐血者編號和病歷,醫護人 員會抽取少量血液樣本作白血球組織 型檢驗。

當閣下被選定為某特定患者進行覆 驗,我們會查詢更多關於閣下的健康 狀況和生活習慣,例如:曾否服用非 處方藥物、性生活、因性取向而可能 經輸血傳播傳染病的風險等。醫護人 員會抽取閣下的血液樣本以檢驗閣下 的白血球組織型、血型和傳染病檢測。

1. Who are we?

Hong Kong Red Cross Blood Transfusion Service ("BTS") is managed by a statutory body, the Hospital Authority ("HA"), and appointed by Hong Kong Red Cross ("HKRC") to operate the Hong Kong Bone Marrow Donor Registry ("HKBMD Registry") in providing Human Leukocyte Antigen ("HLA") typing for bone marrow donors ("donors") and donormatching services for patients requiring unrelated haematopoietic stem cell transplantation ("recipients").

In this Statement, "we", "us" and "our" refer to BTS.

2. What information do we collect?

When you register as a donor, we collect your name, Hong Kong ID number, contact information, date of birth, gender, ethnicity, blood donation history, blood donor ID, health history, and a sample for HLA typing.

When you are selected for confirmatory typing for a specific recipient, we collect more information about your health, behavioral information such as the use of recreational drugs, sex life, sexual orientation which may affect the risk of transfusion transmitted infection, and some blood for HLA confirmatory typing, blood group and infectious markers screening.

Personal Information Collection Statement - Donors

當您已被確定與特定患者配對為脗合並選為造血幹細胞捐贈者,醫護人員會了解閣下的病歷及進行詳細的身體檢查以確保您的健康狀況適合作捐贈及沒有已知的傳染病。

我們會在捐贈後跟進閣下的健康狀 況。

我們可能會從閣下或任何第三方(例如醫院管理局和/或閣下的健康護理提供者)收集上述資料。閣下提供的任何個人資料都完全是自願性質。敞若閣下選擇不向我們提供所須的個人資料,則我們可能無法為閣下安排登記為骨髓捐贈者。

3. 我們收集個人資料的目的是什麼?

當我們為本地及全球需要接受造血幹 細胞移植的患者時,閣下所提供的個 人資料會用於提供白血球組織型搜尋 及配對服務,或用於與移植直接關連 的項目,包括:

- 3.1 聯絡閣下作進一步覆驗、身體檢查、 造血幹細胞捐贈和跟進事宜;
- 3.2 促使捐贈者和受贈者的配對、身體檢 查、造血幹細胞捐贈和跟進事官;
- 3.3 處理賬單及繳費事宜;
- 3.4 可邀請閣下為骨髓捐贈作推廣;

When you are selected for workup for a specific recipient, we collect additional information about your health, collect some blood for performing diagnostic investigations for health screening and infectious markers screening.

When a donation for a transplant is made, we collect follow-up information about your health.

The above information may be collected by us from you or other third parties such as your care team, the HA and/or your healthcare providers. It is voluntary to provide any personal data to us. However, if you do not provide the personal data we request, we may not be able to register you as a donor.

3. What are the purposes of collection of personal data?

The personal data we collect from you will be used to provide HLA typing and donor-matching services for patients requiring unrelated haematopoietic stem cell transplantation (the "Services") and for purposes which are directly related to the Services, which include:

- 3.1 to contact you for further testing, workup, haematopoietic stem cell donation and follow up;
- 3.2 to facilitate the matching of donors and recipients, workup, donation and transplantation and follow up;
- 3.3 to process and administer payments and billings;
- 3.4 to allow us to invite you to publicize the Services;

Personal Information Collection Statement - Donors

- 3.5 評估、規劃和改善骨髓捐贈服務; 3.5 to evaluate, plan and improve the Services;
- 培訓員工,以提供骨髓捐贈服務; 3.6 3.6 to train staff to provide the Services;
- 3.7 促進骨髓捐贈服務的認證、內部審 3.7 to facilitate accreditation, auditing, quality control and 核、質量管理及行政服務; administration of the Services;
- 3.8 處理查詢、意見及投訴; 3.8 to respond to and handle queries, feedback and complaints;
- 3.9 參與通過道德操守審查的研究; 及 3.9 to participate in ethically approved research; and
- 3.10 符合法律和監管規定。 3.10 to fulfil legal and regulatory requirements.

如閣下的個人資料須用於任何其他 We will obtain your consent before using your personal 目的,我們會先徵求閣下的同意。 data for any other purposes.

我們向誰披露閣下的個人資料? 就以上第 3 條所列目的,我們有可能 向以下人士(可能位於香港或海外) 披露閣下的個人資料:

- 4.1 協助我們進行第 3 條所列的第三方 4.1 服務提供者(如行政、資訊科技和收 費服務);
- 4.2 醫院管理局所管轄的機構、香港紅十 4.2 字會、香港骨髓捐贈基金及其各自的 第三方服務提供者;
- 4.3 世界骨髓捐贈者協會及其他國家的骨 4.3 髓捐贈者資料庫;
- 4.4 指定受贈者的授權代表;

4. To whom do we disclose your personal data?

Your personal data may be disclosed to the following persons (who may be located in Hong Kong or overseas) for the purposes set out in section 3 above:

- third party service providers who provide services to us (such as administrative, information technology and payment services) which help us carry out the purposes set out in section 3 above;
- entities controlled by the HA, the HKRC, the Hong Kong Marrow Match Foundation and their respective third party service providers;
- the World Marrow Donor Association and other bone marrow donor registries;
- if you are matched as a donor for a specific recipient, 4.4 authorized representatives of that recipient;

Personal Information Collection Statement - Donors

- 4.5 法定機構的財務部門,如撒瑪利亞基 4.5 金和其他用於處理任何繳款或收款項 目的金融機構;
 - financial departments of statutory bodies such as the Samaritan Fund and other financial institutions for the processing of any monies receivable or payable;
- 4.6 辦理相關保險的保險公司;
- 4.6 insurance companies for the processing of relevant insurance;
- 4.7 專業顧問包括審核員和律師;及
- 4.7 our professional advisers such as auditors and lawyers; and
- 4.8 具法律效力或規例要求的相關政府部 4.8 門、監管機構、法定委員會或執法機 構。
 - relevant government departments, regulators, statutory boards or authorities or law enforcement agencies to comply with legal or regulatory requirements.

在閣下同意的情況下,閣下的個人資料 也可能會披露給任何第三方。

Your information may also be disclosed to any other party with your consent.

5. 如何查閱和更改個人資料

如果你希望根據《個人資料(私隱) 條例》要求查閱/改正香港紅十字會 輸血服務中心持有你的個人資料,請 依本文末段資料在辦公時間內與有關 的資料控制員聯絡。

5. How do you access or correct your personal data?

You have the right under the Personal Data (Privacy) Ordinance to seek access to and correction of the personal data we hold about you. Please contact our data controller via the information at the bottom of this Statement during BTS's office hours.

更新個人資料收集聲明

Changes to this Personal Information Collection Statement

此聲明於二零二二年十二月修訂。

This Statement was updated in [December] 2022.

我們將會不定期審查和更新本聲明。 本聲明的更新將會發佈在我們網站 上,如在收集和處理閣下的個人資料 方面有重要變更,我們將會在網站上 清楚列明或直接與閣下聯絡。

We will review and update this Statement from time to time. Updates to this Statement will be posted on our BTS website and, if any significant changes are made in respect to the collection and processing of your personal data, we will make this clear on our BTS website or by contacting you directly.

Personal Information Collection Statement - Donors

7. 聯絡我們:

如閣下對此聲明有任何查詢或意見, 請在辦公時間內與我們的資料控制員

聯絡:

熱線:2710-1206 傳真:2780-0021

電郵: hkbmdr.coordinators@ha.org.hk

地址: 九龍京十柏道 15 號

此中文聲明條款為英文版本譯本,如中、 英文兩個版本有任何抵觸或不相符之處, 應以英文版本為準。

Contact [us]: 7.

If you have any questions, comments or concerns after reading this Statement, please contact our data controller during BTS's office hours at:

Hotline: 2710-1206 Fax: 2780-0021

Email: hkbmdr.coordinators@ha.org.hk 15 King's Park Rise, Kowloon Address:

This Statement has been translated into Chinese. If there is any inconsistency or ambiguity between the English version and the Chinese version, the English version shall prevail.