

# 支持拯救生命 Support Saving Life

# 登記骨髓捐贈資訊

Educational Pack for Bone Marrow Donor Registration



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# 登記骨髓捐贈資訊

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# Educational Pack for Bone Marrow Donor Registration

# 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 hematopoietic 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!

## 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!
- •成為骨髓捐贈者是自願性及無 償的,登記後您可以隨時選擇 退出。
- 您可能會捐贈予本地或全球需 要進行造血幹細胞移植的患者。

## • 當您被確定為合適的配對時, 我們將安排覆驗,以確認您是 最合適的捐贈者

• 您所捐贈的造血幹細胞,能為 患者帶來痊癒的希望,所以您 的承諾非常重要

# Step 2: Verification **Typing**

Journey to save a life!

Step 3: Work-up

- You have completed step 1 once you registered, your information and HLA typing are stored in HKBMDR's database, and we will contact you if you are a match!
- Being a donor is voluntary and nonremunerated. You are free to withdraw anytime.
- You may be donating to any patient in need of HSC transplant around the world.
- Once you are identified as a potential match, we will arrange follow-up tests to confirm that you are the best match for the patient in need.
- Your committment to donation is important since your donation means a life-saving treatment for a patient.

# 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。

 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
- •香港骨髓捐贈者資料庫將承擔 所有與捐贈相關的費用。
- 您會受意外保險保障。

# Step 4: HSC **Donation**

- You will make donation by either Bone Marrow Collection (BM) or Peripheral Blood Stem Cell Collection (PBSC).
- All out-of-pocket cost related to donation is covered by HKBMDR.
- · You are covered by insurance for event of accident.

# 第五步: 捐贈後跟進

•香港骨髓捐贈者資料庫將會定 期跟進您於捐贈後的身體狀況。

# Step 5: Follow-up

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



# Educational Pack for Bone Marrow Donor Registration

## 常見問題

# 1. 誰可以登記成為骨髓捐贈者?我合資格嗎? 登記資格:

- 年齡介乎 18 歲至 50 歲
- 身體狀況良好
- 沒有患上已知傳染病,例如乙型肝炎、丙型 肝炎、愛滋病

登記時,您須填妥一份健康評估問卷,以確保您 符合捐贈資格。

### **FAQs**

## 1. Who can join HKBMDR? Am I eligible?

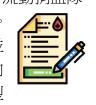
You can join HKBMDR if you are:

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

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

# 2. 如何登記成為骨髓捐贈者?

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。

# 2. 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 do 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 reach the age of 60 or you wish to withdraw from our registry.



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、愛滋病
- 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: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** (calcinosis, Raynaud's syndrome phenomenon, esophageal dysfunction, sclerodactyly and telangiectasia), inflammatory bowel disease or multiple sclerosis
- Endocrine or metabolic diseases, such as diabetes
- Cardiac or respiratory diseases, such as coronary artery disease, myocardial infarction or chronic obstructive pulmonary disease
- Neurological diseases, such as stroke

## 甚麼是骨髓捐贈?

骨髓捐贈是一項在全身麻醉下進行的外科手 術。醫生會使用特製針筒於您的盤骨位置抽取 約800至1,000毫升的「骨髓血液」,而其所含 的造血幹細胞數量一般少於人體內總量的百分 之三(3%)。您的身體可於短時間內自行補充所 捐出的造血幹細胞。



### 3. What is Bone Marrow (BM) Donation?

Bone Marrow Donation is a surgical procedure performed under general anesthesia. 800-1000mL marrow blood will be drawn from the cavity of your pelvic bone by doctor using a special needle, which in general contains less than 3% of the total HSC in your body. Your body could replenish the donated HSC within a short period of time.



骨髓捐贈 **Bone Marrow Donation** 



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## 骨髓捐贈的風險和不良反應

為確保捐贈者安全,捐贈者須通過捐贈前的身 體檢查,並於手術前由麻醉科醫生作身體狀況 評估並解釋全身麻醉程序及風險。一般來說,全 身麻醉的風險是極低的,它可能會引起一些不 良反應,例如噁心、嘔吐、嗜睡、顫抖、頭暈或 甦醒期躁動。抽取骨髓後,您可能會感到傷口位 置有輕微不適、疲倦或僵硬不自然。這些不良反 應通常是輕微和短暫性的。

# 甚麼是周邊血幹細胞捐贈?

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。收集之造血 幹細胞數量會少於一般人體內總量的百分之三 (3%),您的身體可於短時間內補充捐贈的造血 幹細胞。您須在捐贈前 3-4 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 細胞動員至外周邊血液才進行收集。



# Risks and adverse effects associated with Bone Marrow Donation

To assure donor's safety, a medical examination will be conducted prior to donation. In addition, an anaesthesiologist will perform a medical assessment and explain the anaesthetic procedure and associated risks to the donor. In general, the risks of general anesthesia are extremely low. Mild adverse effects may happen after general anesthesia, such as nausea, drowsiness, shivering, vomiting, dizziness, agitation upon awakening. You may experience some pain at the puncture site, fatigue or stiffness after donation. These events are usually short-term and rarely dangerous.

# 4. What is Peripheral Blood Stem Cell (PBSC) **Donation?**

Peripheral Blood Stem Cell (PBSC) donation is a nonsurgical procedure to collect HSC from your bloodstream by apheresis. Less than 3% of your total HSC will be collected and your body could replenish the donated HSC within a short period of time. 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.



周邊血幹細胞捐贈

**Peripheral Blood Stem Cell Donation** 



# Educational Pack for Bone Marrow Donor Registration

## 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)注射常見的副作用包 括輕微骨痛、肌肉疼痛、頭痛或類似感冒等,這 些症狀通常於最後一次注射後一至兩天消失, 這些不良反應通常是輕微的。

G-CSF 已被全球許多衛生部門核准,於癌症患 者及造血幹細胞捐贈者身上常規使用,於捐贈 後我們亦會定期跟進您的身體狀況。

捐贈時,您可能因短暫的低血鈣而導致身體某 些部份出現短暫痲痺(如嘴邊、手指、腳趾)或肌 肉抽筋的感覺。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。

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

## 5. 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。同樣 地,患者的資料也將會被保密。

# 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 flulike symptoms, which usually disappear 1-2 days after the last injection. These events are rarely dangerous.

G-CSF has been approved by many health authorities around the world for regular use in cancer patients and healthy donors, and we offer to arrange follow-up with you regularly after the donation.

You 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, taking calcium supplement or drinks.

You 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.

### 5. 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.



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# 6. 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)。

# 7. <u>誰決定我的捐贈方式?</u>

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。

# 8. 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。

## 9. 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 絡都有不同的政策。在香港,捐贈後的第一年 內,您和患者可以透過 HKBMDR 進行匿名的 書信來往。捐贈一年之後,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 况而安排見面。

## 6. 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 the transplant. This is because the intensive chemotherapy is going to put the patient's life in danger.

## 7. 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.

## 8. 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.

### 9. Can I meet the patient after donation?

Every country has different policy about direct contact between donors and recipients. During the first year of donation, anonymous communication HKBMDR between you and the patient residing in Hong Kong is possible. After the first year, 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.

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

# 私隱聲明 Privacy Policy Statement

## 私隱聲明

#### 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。

# 我們會收集甚麼個人資料以及何時收 集?

我們可能會在不同的情況下收集個人 資料,包括:

## **Privacy Policy Statement**

#### 1. **Policy statement**

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.

#### Who are we? 2.

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 transplantation haematopoietic stem cell ("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;
- 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
- 3.8 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 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.

#### 4.2 Publicity:

- 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.

#### Legal and regulatory obligations: 4.6

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.

#### To whom do we disclose your information? 5.

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:

有關閣下的經歷之相片和影片,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 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 7.

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更新。

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。

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# 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.

# 個人資料收集聲明

# 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。

#### 我們收集個人資料的目的是什麼? 3.

閣下所提供的個人資料會用於為本地 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,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宜;
- 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, haematopoietic stem cell donation and follow up;
- 3.2 to facilitate the matching of donors and recipients, workup, donation and transplantation and follow up;
- to process and administer payments and billings;
- 3.4 to allow us to invite you to publicize the Services;

# 個人資料收集聲明 - 捐贈者

# 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.
- 4. 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;
- 4.4 if you are matched as a donor for a specific recipient, authorized representatives of that recipient;

# 個人資料收集聲明 - 捐贈者

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- 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更新。

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.

# 個人資料收集聲明 - 捐贈者

# 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: 九龍京士柏道 15 號

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#### 7. 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

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