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PRIVACY POLICY

DATRI Blood Stem Cell Donors Registry (“**DATRI**” or “**we**” or “**us**”) respects every individual’s privacy and secures the personal data received for the purposes of operational and legal obligations. DATRI recognizes the importance of the correct and lawful treatment of Personal Data (*as defined below*); This Privacy Policy (“Policy”) provides for maintaining confidentiality of any such information collected by DATRI and shall ensure successful operations within DATRI.

The types of Personal Data that DATRI collects shall include information, including but not limited to:

For Donors:

- Information required to be provided by the Donor in the “Donor Registration Form” (Annexure A), Consent of the donor by signing the consent form (Annexure B), signing the Declaration of Understanding (Annexure C) that they have understood the processes and collecting cheek swab samples to do HLA (Human Leukocyte Antigen) typing. or
- Information received post the medical checkup of the donor (either directly or indirectly); or

For Patients:

- Information provided by a patient or a hospital/medical practitioner; or

For DATRI Employees & Associates:

- Information provided or collected from its employees during the start of engagement with DATRI; or

Any other relevant document or information which DATRI may deem fit to collect or requires for you to provide, in compliance with the DATRI’s internal rules, regulations or policy (collectively referred to as “Personal Data”). This personal data, whether it is held on paper, on computer or other media, will be subject to the appropriate legal safeguards as specified in the Information Technology Act, 2000, the Indian Contract Act, 1872 and as per the applicable laws of India.



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The purpose of this Policy, as amended from time to time, is to give an understanding, on how DATRI intends to collect, store, transfer and use the information provided to DATRI. The Policy may be subject to changes, as required from time to time. Upon updating the Policy, we may revise the "Updated" date at the bottom of this Policy. This policy is applicable to every individual providing any such Personal Data to DATRI.

For the purpose of this Policy,

- “you/You” or “your/Your” shall mean every individual, person, employee, donor, patient and/or discloser of any such Personal Data.
- You shall disclose the Personal Data only to the such person who is authorized to collect data or information on behalf of DATRI, including but not limited to, employees of DATRI, representatives, (authorized) volunteers (collectively called as “DATRI Personnel”)

By providing us your information, you hereby consent to the collection, storage, disclosure, processing and transfer of such information for the purposes as disclosed in this Policy. You are providing the information out of your free will. You have the option not to provide us the data or Personal Information sought to be collected if you do not agree with this Policy.

Further, you will have the option of not to provide your consent, or withdraw any consent given earlier, provided that the decision of not to provide consent / withdrawal of the consent is intimated to DATRI in writing. If you do not provide us personal information or withdraw the consent provided to DATRI with regard to any of your personal information at any point in time, DATRI shall have the option not to provide the benefits for the purpose of which the said personal information was sought.

PERSONAL INFORMATION AND ITS USAGE

The Personal Data collected is used as per the following:

- Every Personal Data of the donor which is provided to DATRI is stored under a unique code, ensuring that the Personal Data is used for the queries received from the patients without disclosing the identity of the individual (“DATRI Database”).
- For fulfilling the objectives and vision of DATRI;



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- maintaining your employment records, and provide you with related benefits and services and to engage in/ carry out the activities that would enable and assist in providing you the benefits and any services arising out of such employment;
- to administer or otherwise carry out our obligations in relation to any agreement you have with us;
- responding to subpoenas, court orders, or legal process, or to establish or exercise our legal rights or defend against legal claims; and
- Investigating, preventing, or taking actions regarding illegal activities, misrepresentations, suspected fraud, or as otherwise required by law.
- For responding to the queries received by DATRI from hospitals/medical practitioners for information regarding the requirement of blood stem cells.
- To manage membership details of the donors and information collected by DATRI during various volunteer functions as and when organized.
- For collecting and processing appropriate personal data only to the extent that it is needed to fulfill operational or any legal requirements;
- For research in the areas of Population genetics, Pharmacogenetics, Disease association, Transplant outcome and other immune and non-immune related genes without revealing the identity of the discloser.

DATRI at all the times:

- meet its obligations to specify the purposes for which personal data is used;
- collects and processes appropriate personal data only to the extent that it is needed to fulfill operational or any legal requirements;
- ensures the quality of personal data used;
- apply strict checks to determine the length of time personal data is held;
- ensure that the rights of individuals about whom the personal data is held, can be fully exercised under the Act;
- take the appropriate technical and security measures to safeguard personal data;



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- ensure that personal data is not transferred from one territory to another, without suitable safeguards.
- procures consents of the discloser for using the Personal Data for any tests or experiments.

Any questions or concerns about the interpretation or operation of this policy should be taken up in the first instance at the time of disclosing the Personal Data to the DATRI Personnel.

DATRI may also remove all the personally identifiable information and use the rest of the data / information for historical or statistical purposes.

You hereby consent that the collection disclosure, storage, processing and transfer of any Personal Data or any other information as disclosed under this Policy shall not cause any loss or wrongful gain to you if the same is used for the purposes stated in this Policy.

AUTHORIZATION

You authorize us to transfer, share, part with your Personal Data, across borders and from your country and jurisdiction to any other countries and jurisdictions across the world (including India), with our agent / third party service provider / partners and other agencies or medical outlets/experts for purposes specified under this Policy or as may be required by law.

SUBJECT ACCESS

All individuals who are the subject of Personal Data held by DATRI are entitled to:

- Seek clarification from DATRI for the kind of information that will be stored in the DATRI Database and the purpose of storing the Information.
- Obtain access to the Personal Data and/or ask any DATRI Personnel on the process of obtaining an access to its Personal Data. You may send such requests, updates (if any) and corrections to DATRI at info@datriworld.org and all reasonable efforts shall be taken to provide you with access to your Personal Information and incorporate the changes (*as notified by you*) within a reasonable period of time.
- Ask DATRI Personnel on the process to update the Personal Data.



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- At any time, ask DATRI Personnel to remove the Personal Data from the DATRI Database, by providing a duly written request at info@datriworld.org and all reasonable efforts shall be taken to remove your Personal Data from the DATRI Database within a reasonable period of time and same shall be notified to you through the Contact information provided by you in the Donor Registration Form.

RESPONSIBILITIES

You shall:

- Check that any Personal Data that you provide to DATRI is accurate and up to date.
- Inform DATRI of any changes to information that you have provided, e.g. changes of address, medical symptoms, etc.

DATRI shall:

- Check and ensure that any information sent out or disclosed by DATRI shall be in accordance to the terms of this Policy.
- Take all necessary safeguards to protect the disclosure of information by DATRI Personnel.
- Ensure that data is kept securely with necessary precautions against physical loss or damage, and that both unwanted access and disclosure is restricted. All DATRI Personnel are responsible for ensuring that any Personal Data which they receive is kept securely and that it is not disclosed either orally or in writing or otherwise to any unauthorized third party.

DATRI aims to comply with requests for access to personal information as quickly as possible, but will ensure that it is provided within 15 days of receipt of a written request unless there is good reason for delay. In such cases, the reason for delay will be explained to the individual making the request.

PRIVACY BREACH

A privacy breach occurs when there is unauthorized access to or collection, use, disclosure or disposal of personal information. Such activity is "unauthorized" if it occurs in contravention of this Policy. An example of a privacy breach is personal information



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becoming lost or stolen or personal information being mistakenly emailed to the wrong person.

DATRI follows the privacy breach incident protocol in accordance with the following five steps.

The first step under this protocol is the responsibility of an individual or individuals who first become aware of the potential breach. The second through fifth steps are the responsibility of the DATRI Personnel, working in cooperation with the necessary stakeholders.

Step 1: Reporting the Breach - Any discloser of the Personal Data who becomes aware of a possible breach of privacy involving personal information in the custody or control of the DATRI, will immediately inform the DATRI Personnel. DATRI Personnel shall inform the incident to his immediate superior ("DATRI Officer"). As soon as the breach has been confirmed to have or have not occurred, the DATRI Officer shall implement the remaining four steps of the breach incident protocol.

Step 2: Containing the Breach - The DATRI Officer will take the following steps to limit the scope and effect of the breach. These steps will include:

- i. Work with respective teams to immediately contain the breach by, for example, stopping the unauthorized practice, recovering the records, shutting down the system that was breached, or correcting weaknesses in security; and
- ii. In consultation with DATRI Personnel's, notify the police if the breach involves, or may involve, any criminal activity.

Step 3: Evaluating the Risks Associated with the Breach - To determine what other steps are immediately necessary, the DATRI Officer, working on the issue, will assess the risks associated with the breach.

Step 4: Notification – If required, a notification detailing the steps taken to rectify the breach of Privacy, shall be issued to the individual whose personal information has been inappropriately collected, used or disclosed.

Step 5: Prevention - Once the immediate steps are taken to mitigate the risks associated with the breach, the DATRI Officer will investigate the cause of the breach. If required, this shall include a security audit of physical, organizational and technological measures.



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DATA DISPOSAL/REMOVAL POLICY

At any time, the individual who has provided the Personal Data to DATRI, has a right to approach DATRI for removal of his/her Personal Data from the DATRI Database, by providing a duly written request at info@datriworld.org. DATRI shall take the reasonable measures and efforts to remove such Personal Data from the DATRI Database, within a reasonable period of time and shall notify the individual via the contact information provided in the Donor Registration Form.

Disclaimer: When a file is deleted, the operating system does not completely remove the file from the disk; rather, the file deletion removes only the reference to the file from the file system table. The file remains on the disk until a subsequent file is created over the original file. However, even after the file is overwritten, it is possible to recover data from the original file by studying the magnetic fields on the disk platter surface. The only way to prevent these kinds of inadvertent file sharing or file access is to appropriately clean (e.g., sanitize) the hard drive or other media by performing a data wipe or over-write, or to physically destroy the hard drive or other media before it reaches its next owner or destination.

DATRI warrants to take all the required measure to ensure that the appropriate data disposal procedures are followed and the data in the systems is erased permanently, by following the appropriate data disposal measures.

SUBJECT CONSENT

The need to process data for normal purposes has been communicated to all data subjects. DATRI agrees that the Personal Data collected is very sensitive in nature, for example information about health, race or gender, and ensure that express consent of the discloser is obtained in order to process the data in the DATRI Database.

RETENTION OF DATA

DATRI ensures that Personal Data shall not be retained in the systems for duration which is longer than, as prescribed under the applicable laws. All DATRI Personnel's are responsible for ensuring that information is not kept for longer duration than necessary, unless specified or required under the applicable laws.

DISCLAIMER



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It is entirely at your discretion, whether or not to disclose the Personal Data to DATRI. You are required to understand that your Personal Data shall be (directly or indirectly) used for a noble cause, at your will. We urge you not to provide any false information or data, if you do not seriously wish to collaborate with DATRI. It is a matter of life and death for those in need of blood stem cells, in an emergency or otherwise.

CONTACTING US

We can address any questions, comments and concerns about our practice with regards to the Privacy Policy. Please write to Ambili Arunkumar at ambili@datriworld.org or reach out to the DATRI Personnel's for any further explanations and clarifications.



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Annexure A

Donor Registration Form



DATRI Blood Stem Cell Donors Registry
DONOR REGISTRATION FORM

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www.datriworld.org

BARCODE :

DATE: _____

You are taking the first step to save a life. Your choice to become a donor can gift a life to a patient in need.

- You can register **ONLY** if
1. You are between 18yrs -50 yrs of age.
 2. You have **NEVER** been diagnosed with HIV AIDS/ Hepatitis B or C / Serious bleeding disorder.
 3. You are in over all good health and meet the medical guidelines.

PRIMARY INFORMATION

NAME: _____
 FIRST NAME _____ MIDDLE NAME _____ LAST NAME _____

DATE OF BIRTH: / /
DD / MM / YYYY MOTHER TONGUE _____

EDUCATIONAL QUALIFICATION _____ *MOTHER'S ETHNIC ORIGIN / RACE _____

MARITAL STATUS: MARRIED SINGLE *FATHER'S ETHNIC ORIGIN / RACE _____

GENDER: MALE FEMALE *Example of ethnic origin: Marwadi, Rajput, Punjabi Sikh, Tamil Mudaliar, Kannada Gowda, Telugu Kamma etc. Please understand that the patient is more likely to find a possible match with in the same race or ethnicity.

HEIGHT: _____ CMS WEIGHT: _____ KGS BLOOD GROUP: _____

CONTACT INFORMATION

Primary Phone Secondary Phone

Primary email _____ Secondary email _____

PERMANENT ADDRESS **ADDITIONAL ADDRESS OF A FRIEND OR RELATIVE**

Line 1 _____ Name _____
 Line 2 _____ Phone _____
 City _____ Relationship _____
 State _____ Address _____
 PIN Code PIN Code

ORGANISATION / EDUCATIONAL INSTITUTION INFORMATION

Company/ Institution Name _____ Emp/Student Id _____

Address _____

I _____ HEREBY CERTIFY THAT ALL THE INFORMATION I HAVE PROVIDED IS CORRECT TO THE BEST OF MY KNOWLEDGE.

Place _____ Date _____ Signature _____

Thank you for your time. If you become a match, we will contact you. In case of any queries, please send an email to info@datriworld.org.
 DATRI/DR/001/V1.1 E.f. 18/FEB/2015



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Annexure B

Donor Informed Consent Form



DATRI BLOOD STEM CELL DONORS REGISTRY

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DONOR INFORMED CONSENT FORM

BARCODE:

The following disclosure confirms my informed consent to be a registered DONOR in DATRI and DATRI's agreement and commitment to me.

1. Any information that is obtained in connection with registering as a donor at DATRI and that can be identified with me, will remain confidential and will not be disclosed to anyone outside the authorized personnel of DATRI's team.
2. I agree to have my sample collected, typed, stored and listed on DATRI's registry to determine if I am a possible match for any patient and also for any other registry purposes.
3. I would like to have my sample HLA typed at any well equipped and experienced lab in the world.
4. I will be given access to my information any time on request.
5. I have read the awareness material and /or have been explained the process of donation.
6. I hereby give consent for the sample donated by me to be used for research in the areas of Population genetics, Pharmacogenetics, Disease association, Transplant outcome and other immune and non-immune related genes without revealing my identity.
7. I will be contacted and asked for further consent for any tests or experiments other than the ones mentioned above. I reserve the right to deny when contacted for further consent on any tests or experiments other than the ones mentioned above.
8. I reserve the right to withdraw from the donation process at any given point of time and I understand that all the previous actions conducted on my sample shall be unaffected by such cessation. I will exercise this right responsibly, since I am aware that withdrawing from the donation process after the donation date is mutually agreed, will be fatal for the potential recipient.
9. I will not receive any monetary benefits for:-
 - a. Participating as a potential donor
 - b. For being chosen as a possible match for any patient
10. I will not be charged for any future expenses or costs related to:-
 - a. Tests for potential donor match
 - b. Procedures carried out in case of being chosen as a possible donor

I have provided DATRI with my complete and correct contact information and agree to keep it updated.

NAME : _____ (in capitals)

SIGNATURE : _____

DATE : _____ PLACE : _____

DATRI/DR/002/V3.1 EFF 26/MAY/2015



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Annexure C

Declaration of Understanding

DECLARATION OF UNDERSTANDING

S.No	Description	Response	Signature
1	I have read and/or been explained the process of Peripheral Blood Stem Cell (PBSC) donation and I understand the process.	YES/NO	
2	I have discussed the process with my parents/spouse/siblings and have their approval to register as a volunteer blood stem cell donor.	YES/NO	
3	I am registering as a voluntary blood stem cell donor because I want on my own accord and have not been pressurized by any one to register.	YES/NO	
4	<p>If I am found to be a match for any patient in need, I will be contacted by DATRI. If I agree to donate I understand that</p> <ul style="list-style-type: none"> a. I am required to give 5 ml of blood for confirming the match b. I am required to go through pre-screening tests as per DATRI protocol at a DATRI approved hospital called The Apheresis Center(AC) c. I can donate my blood stem cells, only if the AC doctor certifies me as fit to donate d. Once I go through the pre screening tests and am found fit to donate, the donation dates will be mutually agreed and fixed e. Once the donation dates are fixed, the patient protocol will commence and withdrawal from donation at this stage would be fatal for the patient f. I will be given Granulocyte Colony Stimulating Factor (GCSF) for 5 consecutive days, leading upto the day of donation g. The process of donation (Apheresis) will approx. be 3 to 4 hours h. I will not be required to pay for anything and will not be paid for donating my blood stem cells 	YES/NO	
5	<p>If I am found to be a match</p> <p>I can take the decision to donate my blood stem cells independently</p>	YES / NO	
6	<p>If the Answer to point 5 is 'NO'</p> <p>I need to take the approval of my parents</p> <p>I need to take approval of my siblings</p> <p>I need to take approval of my spouse</p> <p>I need to take approval of others (Please specify)</p>	<p>YES/NO</p> <p>YES/NO</p> <p>YES/NO</p>	

--end of document--