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A guide to organize voluntary stem cell donors recruitment drive for hematopoietic progenitor stem cell transplant

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Abstract:

BACKGROUND: Hematopoietic progenitor cell transplantation (HPCT) is used as a definitive treatment in hematological malignancies. For a successful HPCT, the donor and recipient should have matching human leukocyte antigens (HLAs). About 25% of patients have a chance of finding matching HLA within family, while rests 75% are dependent on voluntary stem cell donor. Globally, there are 75 stem cell registries with more than 30 million donors registered among which India represents 0.36 million. Therefore, finding a stem cell donor for Indian patient is quite difficult. The aim of the present study is to discuss the significance of voluntary stem cell donor recruitment drive and also to guide the drive organizers and their team for effectively organizing the drive to increase the database of such donors.

MATERIALS AND METHODS: Voluntary stem cell donor recruitment drives are conducted to spread awareness among the people and motivate them to register as a donor. Once the donors have given their consent, the sample is taken and sent to laboratory for HLA typing and the result is uploaded in World Marrow Donor Association, an international association of member to find the best possible matches for patients with hematological disorders.

RESULTS: Genebandhu has organized over 127 recruitment camps since 2012 and recruited 13,000 voluntary stem cell donors. HLA typing of 7446 donors has been completed. Out of this small number of typed donors, 11 lifesaving HPCTs have been successfully facilitated.

CONCLUSIONS: Here, we have demonstrated guidelines along with steps to organize voluntary stem cell donors recruitment drive that is needed to increase number of donors, thus increasing significantly the chances of saving many vital lives.

Keywords:

Donor drive, hematopoietic progenitor cell transplantation, human leukocyte antigens, stem cell donor

Introduction

Hematopoietic progenitor cell transplant (HPCT) is standard care of treatment for various hematological disorders.^[1] Only 30% availability of a human leukocyte antigen (HLA)-matched related donor for a patient in need of an HPCT has led to the recruitment of

unrelated volunteer stem cell donors database worldwide.^[2] These unrelated donors are known as matched unrelated donor (MUD). Currently, more than 31 million MUD registered globally, whose data are interlinked to a central hub known as the World Marrow Donor Association (WMDA).^[3] Ethnicity also plays a major role in finding a MUD and possibility of succeeding HPCT;^[4] therefore, it is even more difficult to find the donor

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with compatible HLA in India with such a huge population and multiple diversity. In the year 2014, a study revealed that the likelihood of finding a MUD for an Indian patient in the global registries is 16% and a dismal 0.008% in the Indian registries (donors in Indian registries were just 33,678 as compared to 22.5 million in Bone Marrow Donors Worldwide). These significantly emphasizing on enhancing the number of Indian donors in both Indian and global registries.^[5] In another study in 2014 reveals in a group of 18,000 donors, only 19% of patients found a MUD at 10/10 low-resolution level. The chances of finding a donor at high-resolution 10/10 level were even less. The major limitations were lack of awareness, patient's economic status, unavailability of MUD, lack of funding for the function of registry, and high donor dropout rates.^[6] In 2008, a report revealing 1540 bone marrow transplants (BMT) were performed at six BMT centers between 1986 and 2006 across India, but no record for MUD was available.^[7] In a population-based study in the year 2014, the mean percentage of individuals who would have a 10/10 adult donor match within India ranged from 14.4% with a registry size of 25,000 to 60.6% with a registry size of 1,000,000. The percentage of matches increased exponentially with increased registry size.^[8] At present, four Indian registries have approximately 0.36 million Indian donors registered with WMDA.^[3] Looking at the current situation, there is a raise in number of patients seeking HPCT. The aim of this article is to discuss about the importance of voluntary stem cell donor and to guide the camp organizer, medical officer, and also other team members involving involuntary stem cell donor recruitment drive to organize the camp efficiently. Voluntary stem cell donor drives are organized to spread awareness among the people and to motivate them to register themselves as MUD in the database. The primary aim is to reach to the masses and unite them on this database so that chances of saving many lives are increased significantly.

Materials and Methods

Planning

Planning should be the first step toward preparing for a drive. It is important to critically plan a drive such that the purpose of the drive should be clearly and effectively conveyed in the best possible way to motivate each and every person to join the stem cell registry. Donor recruitment site can be in-house or out-house; in-house (i.e., at the fixed office premises of Genebandhu) and out-house location (for example, colleges/universities, business offices, and regional places). A plan must be assignable, realistic, time-based, and specific. Steps involved in the planning are as follows:

- a. Estimation of the number of volunteers required for the drive depending on the number of persons

expected to participate. For example, if number of expected person is 100, minimum of 5–6 volunteers will be needed for the drive

- b. Assigning of task to each volunteer: The list of tasks is mentioned below:
 - i. Presentation
 - ii. Individual answering the queries
 - iii. Distribution of the registration form
 - iv. Assistance for filling the registration form
 - v. Collection of registration forms
 - vi. Sample collection
 - vii. Distribution of feedback forms
 - viii. Feedback forms collection.

Preparation

It should follow the timeline described in the planning phase, wherein interests of the donor are engaged by various means including presentation and information booklet as detailed below:

- a. Presentation preparation. The presentation should address the following contents:
 - i. Purpose of the drive
 - ii. Information about the need of the stem cell donor database
 - iii. Procedure of sample collection
 - iv. Benefits of donation
 - v. Side effects (if any) of donation.
- b. Information booklet
Information booklet should be available at the donor recruitment site having all the basic information for the appropriate information as well as the mode of transmission to be given to volunteer hematopoietic stem cell (HSC) donors at all stages, from initial recruitment, through final selection for donation, to postdonation.^[9] Information which will be provided to the volunteers during donor recruitment drive must include the following:
 - i. Printed material – (leaflets and posters)
 - ii. Verbal presentations
 - iii. Electronic mail
 - iv. The World Wide Web.

This information should contain details of need of stem cell donor database, magnitude of the problem, eligibility criteria for registering as a stem cell donor, rights of voluntary stem cell donor, and information about stem cell collection process.

- c. Registration cum consent form:
Registration form is designed to collect the basic demographic information of the registered donor. In addition to this, preliminary donor health screening information is also included in this form.

Donor recruitment

Major steps involved in voluntary stem cell donor recruitment drive are summarized in Table 1.

Table 1: Steps involved in voluntary stem cell donor recruitment drive**Steps**

Counseling of the interested persons with age group between 18 and 55 years willing to register as donor

Registration and consent

Sample collection

HLA test of the collected sample

Updation of HLA reports in WMDA

HLA = Human leukocyte antigens, WMDA = World Marrow Donor Association

Counseling of the interested persons willing to register as donor

Information which needs to be given during counseling should include both the rights as well as responsibilities of the donor as mentioned below:

- i. Hematopoietic progenitor cell (HPC) donation is undertaken voluntarily, and withdrawal of the volunteer is permitted at all times
- ii. Registration of a donor implies a general offer to be available for any patient in need of a HPCT anywhere in the world, irrespective of the patient's age, gender, nationality, and ethnicity. It should be made clear to volunteers that patients are only eligible for transplant as per the WMDA standards
- iii. The volunteer, with age group between 18 and 55 years, should be informed that he/she need not to donate immediately. Once his/her HLA typing and personal data are entered into the registry, further blood samples may be requested, as and when required in the future
- iv. The volunteer is requested to inform the registry for any changes in:
 - a. Contact addresses and telephone numbers
 - b. Changes in medical status, including pregnancy or other conditions that may preclude donation temporarily or permanently
 - c. His/her commitment to remain in the registry
 - d. The volunteer must understand that certain diseases in a donor may disqualify him/her for HPC donation. At the time of recruitment, the volunteer must complete and sign a medical questionnaire
 - e. The volunteer must be informed that blood samples or buccal swabs will be used primarily for histocompatibility (HLA) testing, blood grouping and Infectious Marker (IDM) testing relevant for the registry file, donor search processes, HPC donation, and transplantation. Any use of stored material for purposes other than those related to HPC donation and transplantation must require an additional and specific written consent from the donor.

Registration and consent

A simple, comprehensible consent form is to be signed by the volunteer, which confirms that he/she understands and agrees to the following:

- i. Join the Registry as a potential MUD and provide samples for HLA typing
- ii. The principles and risks of HPC donation and the implications of transmission of infectious diseases from donor to patient
- iii. Be available to the donor center for further requests to provide blood samples for additional histocompatibility testing and possibly to provide HPC for transplantation
- iv. Complete a medical evaluation questionnaire
- v. Donation for any recipient in need
- vi. The confidentiality of personal data.

Sample collection

Either blood or buccal swab sample should be collected for HLA test.

Human leukocyte antigen test of the collected sample

Collected sample is sent to laboratory for performing the HLA typing.

Updation of human leukocyte antigen reports in World Marrow Donor Association

Subsequently, HLA typing result is uploaded in WMDA so that it is accessible in the future.

For conducting the donor drive, there are important points that need to be remembered. These can be categorized as follows:

- a. On the day of drive
- b. Day after the drive
- c. Follow-up of registered stem cell donor.
 - a. On the day of drive
 1. Recheck all the essentials
 2. Start early so that the drive starts on time
 3. Setup the banner/poster and keep everything in place
 4. Deliver the presentation. Make sure that the audience connects to the presentation
 5. Resolve queries in the best possible way
 6. Get the registration forms filled from the interested people
 7. Collect samples
 8. Attach the registration forms with their respective sample
 9. Give the certificates and tokens of appreciation
 10. Click pictures
 11. Distribute the feedback forms
 12. Collect feedbacks.
 - b. Day after the drive
 1. Express your gratitude toward the host organization either through E-mail or by personally contacting the concerned person
 2. Analyze feedback forms and make amendments, if required
 3. Send samples for HLA typing

4. Upload the HLA reports on the database.
- c. Follow-up of registered stem cell donor
In addition to donor recruitment, donor retention is a tough task for a stem cell registry. Dedicated donor counseling and committed staff, which are willing to understand problem and exploring the best possible way to make donors understand the need for the issue, are required. Recruited donors are welcomed with the mail and birthday wishes. Telephonic conversation is done after every 6 months to check health status of the donor. Monthly newsletter is also shared with every registered donor.

Results

Genebandhu,^[10] a stem cell registry operating from North India, has organized over 127 stem cell recruitment drives since 2012 and recruited approximately 13,000 donors [Table 2]. Till date, HLA typing of 7446 donors, who have consented to donate HPC, has been completed and uploaded in WMDA. From this small number of HLA-typed donors, Genebandhu has successfully facilitated lifesaving 11 hematopoietic progenitor cell transplant (HPCT).

Conclusions

With increase in population and development of more advanced hematological disorders, the need of voluntary stem cell donor is an immense need of society. By gaining valuable skills and experience in the process of recruitment of donors, a stem cell donor himself could serve as an ambassador for recruiting further donors by devoting their time during the weekends for this noble cause as well as making people aware and promoting it through various platforms of social media which are currently very popular among the youth. For an Indian patient, this genetic matching is difficult to find, as the number of registered donors from India is still very low.

Table 2: Representing total numbers of volunteer donors registered from 2012 to 2017

Year	Number of donors recruited
2012	80
2013	223
2014	2600
2015	2739
2016	3820
2017	3538
Total	13,000

In addition, population of Indian subcontinent exhibits abundant genetic segregation and wide subclustering that may be attributed mainly to evolutionary history and endogamy. Indian population has inherent diverse extent of lineage from their ancestors. In finding a MUD for HPCT, the extinction of a large diversity of HLA alleles and haplotypes of other ethnic groups in the Indian subcontinent poses additional challenges. Here, we have demonstrated guidelines along with various steps to organize voluntary stem cell donors recruitment drive that is necessary to increase number of donors, thus increasing significantly the chances of saving many vital lives.

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Conflicts of interest

There are no conflicts of interest.

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