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# Augmenting bone marrow donor registries to enhance diversity and participation

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## Abstract:

Bone marrow contains stem cells which produce blood corpuscles and is crucial for the survival and well-being of an individual. Successful transplantation essentially requires a close match between the donor's and recipient's human leukocyte antigens (HLAs), and because these HLA markers are inherited, patients generally find a match within their own ethnic or racial group. The objectives of the current study were to identify the need for diversity in bone marrow registries, enlist potential barriers to participation in bone marrow donation, and proposed targeted interventions to overcome these identified barriers. There arises the need to maintain diversity within bone marrow donor registries, as this gives a platform for patients from underrepresented population groups to encounter fewer problems in locating compatible donors. Although bone marrow donation has emerged as the need of the hour for the treatment of life-threatening illnesses, we have not been successful in promoting bone marrow donation across different settings and in different communities. In conclusion, despite the bone marrow donation process being generally safe, we have failed to promote the registration of donors from diversified groups. The need of the hour is to strengthen awareness activities and support potential donors to not only promote registration but also enhance access to potentially life-saving treatment.

## Keywords:

Aplastic anemia, bone marrow, diversity, ethnic, hematology, leukemia, lymphoma, malignancies, registries

## Introduction

Bone marrow contains stem cells that produce blood corpuscles and is crucial for the survival and well-being of an individual.<sup>[1]</sup> However, when bone marrow is damaged or destroyed due to a disease or chemotherapy, a transplant of healthy stem cells from a donor can aid in the restoration of normal blood cell production and immune function.<sup>[2]</sup> In other words, bone marrow donation is crucial in treating life-threatening blood disorders, such as leukemia, lymphoma, aplastic anemia, and some immune and metabolic

conditions.<sup>[2]</sup> Successful transplantation essentially requires a close match between the donor's and recipient's human leukocyte antigens (HLAs), and because these HLA markers are inherited, patients generally find a match within their own ethnic or racial group.<sup>[3]</sup> There arises the need to maintain diversity within bone marrow donor registries, as this gives a platform for patients from underrepresented population groups to encounter fewer problems in locating compatible donors.<sup>[4]</sup> The objectives of the current study were to identify the need for diversity in bone marrow registries, enlist potential barriers to participation in bone marrow donation, and proposed targeted interventions to overcome these identified barriers.

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## Diversity in Bone Marrow Registries: The Need

There is a definite need to maintain diversity in bone marrow registries, as existing registries predominantly consist of donors from majority populations, whereas people from minorities lack any representation.<sup>[5]</sup> This lack of diversity significantly contributes to inequity in access to life-saving treatment, resulting in either a delay in treatment or no options for transplants.<sup>[6]</sup> In fact, in the process of locating a compatible donor, a significant time is lost, augmenting the risk of progression of disease or development of complications, and this directly leads to lower survival rates.<sup>[3]</sup> If we succeed in maintaining broad genetic, racial, and ethnic representation, it will increase the overall pool of HLA types, promote health equity, and enhance the chances of matching for all populations.<sup>[3,4]</sup> In addition, a diverse registry strengthens international collaboration, builds community trust in healthcare delivery systems among marginalized population groups, and will also support the nation's vision to provide equitable opportunities for treatment irrespective of the background.<sup>[4,6,7]</sup>

## Potential Barriers to Participation in Bone Marrow Donation

Although bone marrow donation has emerged as the need of the hour for the treatment of life-threatening illnesses, we have not been successful in promoting bone marrow donation across different settings and in different communities.<sup>[1,8-13]</sup> This can be attributed mainly to the lack of awareness about different aspects of bone marrow donation, and the presence of various myths (like it is an extremely painful procedure, potential risk of bone marrow depletion or complications, concerns about how genetic or health data will be used, fear of discrimination based on genetic information, etc.), which have discouraged people from donating bone marrow.<sup>[1,8,9]</sup> In continuation, many people are afraid of needles, anesthesia, or surgical procedures, due to which they are reluctant, even though most donations are performed in today's era through peripheral blood stem cell collection.<sup>[9]</sup> In many minority communities, owing to the absence of prominent stories of donors (role models) or recipients, the rest of the community fails to consider it as personally relevant or achievable.<sup>[10]</sup>

We cannot rule out the presence of cultural beliefs and traditions (like bone marrow donation will interfere with body integrity) and religious concerns (namely, these procedures are against religious principles) in different minority communities, and they have also emerged as a significant barrier in not sustaining diversity in bone marrow donation.<sup>[9,11]</sup> The next concern

is the limited presence of culturally representative recruiters in different outreach initiatives, reducing engagement and connection with the targeted minority representatives.<sup>[12]</sup> In fact, nonnative or minority communities tend to struggle to comprehend registration materials or informed consent documents, especially if they are not available in multiple languages.<sup>[12,13]</sup> Further, prior history of discrimination significantly contributes to mistrust among minority communities, which makes these people often question their role toward bone marrow donation programs.<sup>[9]</sup> There is often lots of inconvenience involved (such as paperwork, traveling for confirmatory testing, multiple appointments, etc.), which discourages busy individuals regardless of initial interest.<sup>[9,10]</sup> Even though the donors are not charged for this procedure, indirect costs tend to discourage participation if reimbursement is not guaranteed.

## Targeted Interventions

Acknowledging the importance of bone marrow donation in minority population groups and the presence of multiple barriers that limit their fullest participation, there is an immense need to adopt targeted public health interventions to enhance diversity and participation in bone marrow donor registries.<sup>[2,9,13-21]</sup> The first set of interventions deals with community-based education and awareness campaigns, wherein the health sector must liaise with trusted community leaders (such as religious leaders, faith leaders, and elderly representatives), building trust and credibility to organize such sessions, including recruitment events.<sup>[14,15]</sup> The effectiveness of these sessions can be further enhanced by incorporating testimonials and real-life success stories of donors and recipients from underrepresented groups to encourage participation and make donations personally relevant.<sup>[16]</sup> In addition, donor education and recruitment drives can be organized in schools or colleges to target young and healthy potential donors.<sup>[17]</sup>

To appeal and actively engage donors from different ethnic, cultural, and religious backgrounds, it is a must that the designed educational material is multilingual and should consider the literacy levels and cultural values of the targeted communities.<sup>[18]</sup> These campaign materials should also explore the possibility of including visual media to represent diverse individuals to facilitate inclusion.<sup>[18]</sup> In addition, these designed messages must target the common myths and cultural or religious barriers or misconceptions to encourage better representation of these diversified populations.<sup>[8]</sup> The impact and reach of these awareness campaigns can be significantly enhanced by launching activities through various social media platforms to reach remote and underrepresented communities.<sup>[13]</sup> However, as mentioned above, the content must be customized culturally and linguistically

and should have the details to promote the registration of minority donors through mobile-friendly websites and applications.<sup>[14,15,18]</sup>

The sustainable approach would be to integrate bone marrow donor registries with the existing public health programs by training healthcare professionals from primary care settings about bone marrow donation and common misconceptions.<sup>[19]</sup> In fact, donor registration services can be started at immunization clinics, blood donation sites, or other screening events, as this will simultaneously target the present crowd. Moreover, employers and labor unions of minority workforces can also be targeted to conduct education sessions and encourage on-site registration drives. However, the success of these workplace-based initiatives will also depend on the implementation of policies to promote paid leave for giving time for donors to recover, job security, and legal provisions to discourage genetic discrimination.<sup>[2,20]</sup> Furthermore, donors must be provided with financial support (for their travel, accommodation, etc.) to reduce financial load, especially for low-income participants.<sup>[20]</sup> Finally, there is a definite need to streamline paperwork, discourage unnecessary testing, and standardization of entire bone marrow donation procedure to make their participation convenient without jeopardizing their safety and ethics.<sup>[9,21]</sup>

## Conclusion

Despite the bone marrow donation process being generally safe, the lack of awareness and the presence of misconceptions have significantly contributed to the limited registration of donors from diversified groups. The need of the hour is to strengthen awareness activities and support potential donors to not only promote registration but also enhance access to potentially life-saving treatment.

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## Conflicts of interest

There are no conflicts of interest.

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