Genetic findings of potential donor origin following HCT: Recommendations on donor disclosure and genetic testing

Guidelines from the Medical Working Group of the World Marrow Donor Association (WMDA)

Study details:

The WMDA has established guidelines on genetic testing after allogeneic hematopoietic cell transplant (alloHCT). This study examines the implications of post-transplant genetic testing, particularly the detection of genetic and molecular abnormalities potentially originating from donors. Given the increasing routine use of extensive genetic testing post-transplant, the study addresses challenges in identifying the origins and significance of detected variants and emphasizes the need for guidelines on consent, testing, and donor notification to ensure donor safety and autonomy.

Conducted by the Medical Working Group of the WMDA, the research focused on volunteer unrelated donors who have donated bone marrow, peripheral blood stem cells or mononuclear cells for patients undergoing alloHCT. While some information may apply to related donors, these guidelines primarily address unrelated donor contexts.

Results at a glance:

- **Pre-donation testing:** Routine genetic screening of all donors is not recommended.
- **Post-donation testing:** Testing should be performed only when necessary, avoiding undirected blanket testing. Transplant centers should be mindful of the implications for donors and follow a structured process for reporting and handling findings.
- **Terminology:** Use "donor-derived" only after confirmation through appropriate testing; otherwise, use "genetic findings of potential donor origin."
- **Step-by-step guidelines:** See the figure below.

Figure: Step-by-step guidelines to validate potential donor-derived findings.

Step	Recommendation
Evaluate test validity and likelihood	Ensure registries receive necessary information from transplant centers to determine if an abnormality is donor-derived.
Clinical significance and actionability	Assess if findings are clinically significant or actionable.
Ethical and legal considerations	Ensure donors are informed about potential post-transplant genetic testing.
Genetic rounseling and testing referral	Provide recommendations for counseling and referrals.
Follow-up considerations	Establish follow-up protocols.
Sharing practice recommendations	Promote consistent practice recommendations.

Clinical impact:

NMDP[SM] and other registries play crucial roles in providing life-saving cells while ensuring the care and safety of both recipients and donors. As genetic testing post-transplant becomes more prevalent and complex, robust guidelines for consenting and disclosing findings are essential. These guidelines support registries and transplant centers in conducting safe and effective transplants while protecting donor health and rights. NMDP has established a thorough process for managing genetic findings of potential donor origin, demonstrating a commitment to ethical donor care, ensuring transparency, honoring donor preferences, and providing necessary support throughout the donation process.

Scan to review more recent clinical research

Read the publication in Transplantation and Cellular Therapy (DOI: 10.1016/j.jtct.2023.11.019).

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