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Title: Policy for Sharing Post-Transplant Anonymous Correspondence

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POLICY

POLICY STATEMENT

It is the policy of the National Marrow Donor Program®/Be The Match® (NMDP) that donor or recipient consent is provided prior to sharing post-transplant anonymous correspondence internally within NMDP or externally.

BUSINESS SECTION/DEPARTMENT

This policy applies to the Post-Transplant Communication team, Donor Services, and all staff who handle post-transplant anonymous correspondence.

<u>PURPOSE</u>

This policy clarifies the practice of sharing post-transplant anonymous correspondence internally within NMDP and externally (e.g., Network partners, social media, etc.).

SCOPE

This policy applies to all NMDP employees who handle post-transplant anonymous correspondence.

RELATED DOCUMENTS

- 1. <u>A00500, Procedure for Obtaining Post-Transplant Consent to Release Personal</u> Information
- 2. A00501, Anonymous Correspondence and Gifts: Policies and Procedures
- 3. A00718, Glossary for Use in NMDP Operations Standard Operating Procedures
- 4. F00776, Post-Transplant Consent Form to Release Personal Information
- 5. <u>F00778, Post -Transplant Consent Form to Release Personal Information After Recipient Death</u>
- 6. F00878, Post Transplant Consent Form to Release Personal Information Spanish
- 7. <u>F00879</u>, <u>Post-Transplant Consent Form to Release Personal Information after Recipient Death Spanish</u>
- 8. F01367, Post-Transplant Consent to Share Anonymous Correspondences
- 9. <u>S00508</u>, <u>Anonymous Donor Correspondence and Donor Consent to Release of Personal Information</u>

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DEFINITIONS

A00718, Glossary for Use in NMDP Operations Standard Operating Procedures

RESPONSIBILITIES

NMDP staff who handle post-transplant anonymous correspondence are responsible for obtaining and documenting consent from the author (i.e., donor, recipient, or recipient's first (1st) degree relative) who initiated correspondence prior to sharing the anonymous correspondence internally within NMDP or externally.

Post-Transplant Communication staff are responsible for reviewing anonymous correspondence, redacting information to ensure anonymity, and retaining a record of the anonymous correspondence approved for sharing.

REQUIREMENTS

- 1. The Post-Transplant Communications team will review anonymous correspondence and, if applicable, redact information to ensure anonymity.
- 2. NMDP staff will obtain and document verbal approval from the author who initiated correspondence prior to sharing anonymous correspondence internally within NMDP.
- 3. NMDP staff handling anonymous correspondence will notify the Post-Transplant Communications team (connections@nmdp.org) when approval to share anonymous correspondence is received.
- 4. The Post-Transplant Communications team will keep a record of anonymous correspondence shared.
- 5. NMDP staff will watermark/make prominent notation of "for internal use/dissemination only" on anonymous correspondence prior to sharing internally.
- 6. NMDP staff will contact the author who initiated the correspondence to request sharing externally only after the donor and recipient, or recipient's first (1st) degree relative, have exchanged F00776, Post-Transplant Consent to Release Personal Information or F00778, Post -Transplant Consent to Release Personal Information After Death, as applicable.
- 7. NMDP staff will obtain written consent from the author who initiated the correspondence using F01367, *Post-Transplant Consent to Share Anonymous Correspondences* prior to sharing the anonymous correspondence externally.

REFERENCES

Not applicable.

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REVISION HISTORY

Revision	Brief Description of Revision
P00147 rev. 1	New Policy

ADDENDA

Not applicable.