National Marrow Donor Program® / BE THE MATCH®

SOCIAL MEDIA CONFIDENTIALITY GUIDELINES FOR NATIONAL MARROW DONOR PROGRAM®/BE THE MATCH® NETWORK PARTNERS

This document is designed to provide guidance and social media best practices for maintaining donor and patient confidentiality. It is critical to maintain donor and patient anonymity to ensure privacy for both the donor and patient, as required by law. These recommendations are designed to guide the social media engagement of individual centers, and are not intended to guide donor or patient use of social media.

Who should use this document?
Maintaining donor and patient confidentiality is a shared responsibility among all center staff, regardless of role.

This document is designed for staff who:

• Actively engage on social media for their center (i.e., marketing, recruitment); or

• Contribute content to their center's social media accounts; or

• Have direct contact with donors and/or patients.

What can (and can't) I share on social media?
The following pages contain guidance on what your center needs to know when sharing content, images or videos about donors and patients on social media.

Please reference S00339 *Confidential Information Standard Operating Procedure (Donor/Patient Confidentiality)* for definitions of donor-identifying, patient-identifying and personal information.

Certain types of information should not be shared on social media due to the broad, public reach of online channels. This includes the location of the donor or patient, the donor or patient ID numbers, or the exact date of the donation or transplant.

Other types of information can be appropriate to share, as long as generalities are used. This includes donor or patient age group (i.e., child, teenager, adult), and the patient's disease.

DO SAY "Jennifer, a student, donated marrow to a **child** with **leukemia.**"
DON'T SAY "Jennifer, a student, donated marrow to a **5-year-old boy** with **ALL**."

Almost everything posted on social media is time stamped, so your center may inadvertently share more information about an event's timing than anticipated. Use generalities if your center wants to reference a certain timeframe.
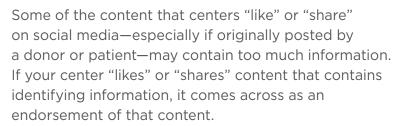
DO SAY "Mary **recently** received a marrow transplant."
DON'T SAY "Mary received her transplant **last Friday,**" or "Jennifer donated **today.**"

Some media articles or existing stories (such as center-generated case studies or blog posts) contain too much information about a donor or patient. Just because the information is already public doesn't mean that your center should also share it on social media.

DO REVIEW the article content thoroughly before posting or linking to ensure all details are appropriate to share.
DON'T ASSUME that existing stories follow confidentiality rules, or post or link to the stories without proper screening.

Some of the content that centers "like" or "share" on social media—especially if originally posted by a donor or patient—may contain too much information. If your center "likes" or "shares" content that contains identifying information, it comes across as an endorsement of that content.

DO REVIEW all content posted by others before hitting "like" or "share" to ensure the information is appropriate.
DON'T ASSUME that it's OK to repost since the information is already out there.

> If you see a media article that contains **too much identifying information** about a donor or patient, please **send a link to the article to media@nmdp.org.**

IT'S GOOD PRACTICE for your center to have publicity consent forms for donors and patients who are featured on your center's social media accounts. However, having a publicity consent form on file doesn't give your center permission to publicly disclose additional identifying details about patients or donors—or details about their donor or patient.

REMEMBER: **YOUR OWN SOCIAL MEDIA**

All these guidelines **also apply to your personal social media accounts**. Please reference your center's individual staff policies for more information about acceptable personal use of social media.

WHAT SHOULD I DO **IF I SEE A BREACH IN DONOR OR PATIENT CONFIDENTIALITY** ON SOCIAL MEDIA?

Breaches caused by donors, patients, families or community members:

If a donor, patient or community member posts too much information to your center's page or tags your center's social media account, it is recommended that your center removes the post, privately messages the individual to explain why the post was removed, and encourages them to repost without identifying information.

Your center may also choose to include a "right to remove" policy statement on all social profiles.

Breaches caused by center:

If your center posts too much information on a social media account, the post should be removed and any breach reported to the National Marrow Donor Program/Be The Match under S00339 *Confidential Information Standard Operating Procedure (Donor/ Patient Confidentiality),* § 3.2, NMDP Network Reporting of Confidentiality Breaches.

REMEMBER: **SOCIAL MEDIA LASTS FOREVER**

If you have any questions about what is acceptable to share on social media, please contact **advocate@nmdp.org.**