

NMDP Facebook Donor Community: Internal Guidelines

Donor Community Purpose and Audience:

- The Donor Community is a private group on Facebook where recently matched donors and past donors connect with each other to ask questions and gather information, share and hear about donation experiences, seek support, and make informed donation decisions. The group should be promoted with past donors and potential donors at Search and WU.

Donor Community Parameters:

- The Donor Community requires an admin to approve members. The group can be found organically through a Facebook group search, so anyone can request to join. The name, member list and group description can be seen by the public; however, posts in the group are private.
- Potential and past donors from DC001 and all U.S. contracted donor centers can be invited or request to join the group. The Community Manager will approve the request if the individual meets criteria.
- Guidelines for group participation are shared in a pinned post at the top of the Donor Community. Expectations for participation are clear and encourage a positive member experience while enabling the Community Manager to enforce the rules when necessary.

Donor Community Management:

- **Approving requests to join:** A request to join will prompt three screening questions to verify eligibility to participate. The Community Manager will approve requests based on answers to the following questions as well as confirmation of status in STAR Link:
 - What is your full name (first & last as listed on the NMDP registry) and your date of birth (month, day and year)?
 - Have you been contacted by NMDP about matching a patient, or have you donated marrow through NMDP before?
 - What was the password provided by your NMDP representative to join this group? (Note: members invited to be part of this group by WU specialists and Search will be provided a password.)
- **Declining requests to join:** If someone requests to join and cannot accurately answer the screening questions and the Community Manager is unable to verify status in STAR Link as either a past donor or potential donor at search or WU, the request will be declined and a message will be sent to the individual.
- **Responding as NMDP:** The Community Manager will respond to unanswered questions within 24 hours (M-F) and within 48 hours on weekends. If a donor posts inaccurate information in the group, the Community Manager may respond with a correction.
- **Content seeding:** The Community Manager will post content within the community when relevant, but will not weigh in on the conversation unless it is necessary to correct inaccuracies.
- **Removing/hiding posts:** Per the guidelines for participation, the Community Manager has the right to remove or hide the following:
 - posts that are false, inaccurate or misleading

- posts that are inappropriate or offensive, including posts that are harassing, abusive, obscene or hateful
- posts that promote commercial products, businesses or fundraising pages
- posts that promote illegal activities
- posts that breach donor/patient confidentiality
- **Managing access:** The purpose of the group is to provide potential and past donors a safe, comfortable place to connect, ask questions and learn from each other's experiences. While a "captive audience" of donors is appealing to many in the organization, the Donor Community should be used only for its intended purpose.

Managing Confidentiality Breaches:

- Given the private nature of the Donor Community, it's OK for donors to share a bit more information within the group than on our public social media pages. For example, a donor referring to their donation date won't be considered a breach of confidentiality.
- If a post including too much personal identifying information (based on existing social media guidelines), is determined to be a confidentiality breach, the Community Manager will privately message the poster to request that the concerning information be removed within 24 hours for confidentiality reasons. If the original post hasn't been edited or removed by the poster in that timeframe, the Community Manager will hide it from public view.