

Social Media Guidelines for Patient Appeals

At DKMS, we encourage patients to share their story on social media, as this can be an incredibly effective way of motivating people to register as blood stem cell donors. Your story is unique, authentic, and can help raise awareness for our mission.

These guidelines apply to both patients and initiative groups who want to motivate the public and tell their story. The guidelines refer to all social media channels like Facebook, Instagram, Twitter, Youtube, Tiktok, and LinkedIn – as well as personal blogs, TV, radio, newspapers, and magazines.

Why are the guidelines important?

It is our priority to protect the data and privacy of our patients and donors. According to national regulations, a blood stem cell donation must be done anonymously. This means you are not allowed to meet, make direct contact with, or even know who the donor is for a set period of time post-donation, though for some countries you may never be allowed to meet. This is done for several important reasons:

- While you are focusing on your recovery, it might be too much of an emotional burden to know or meet the person who donated the stem cells.
- After a successful donation, the donor is reserved for you for two years, in case another stem cell donation is necessary. Anonymity allows the donor to make this decision free from emotional pressure.

With these guidelines we want to ensure that information shared on social media cannot be used to identify you or the donor. At the same time, we still want to encourage you to tell your story on social media.

Creating an emotional patient appeal

A patient appeal is most successful when it is emotional, tells the unique story of the patient and allows people to connect personally to the appeal. Here are some questions to help inspire you:

- What was your life like before the diagnosis?
- How did you feel after the diagnosis?
- How is your current physical condition and what are the next steps of therapy?
- Why is a stem cell transplantation so important for you?
- How did your family and friends react when they heard about the diagnosis?
- What are your hobbies and interests?
- What do you want to achieve in your life? What are your wishes for the future?
- What would you say to people who are thinking about registering as a potential donor?

Also, try to let your community be part of your whole journey. Postings about updates like “donor is found” or “day zero” are great ways to engage with your community.



Do share

- The fact that you are waiting for or received a second chance at life because of a blood stem cell donation
- The fact that you are currently recovering in hospital or an update on your physical condition
- The story of your blood stem cell transplantation and your support of DKMS
- Details about yourself to help people personally connect with the appeal, such as your name, hobbies, and your location (region or country). You can also tag your favorite musicians, bands, sports team to let them know what their fans are dealing with and maybe get some reach.



Don't share

- Specific and confidential details about your donor (e.g. age, gender or exact location)
- The name or exact location of the hospital
- The date of the transplant
- Your date of birth or exact address (please be extra careful if your donor is coming from the same country as you are)

What does this mean for my photos and videos?

The same rules apply to photos and videos – they should not provide information on your identity or the identity of the donor. Please consider the following:

- Please do not publish photos which identify the date or location (e.g. hospital name/logo, landmarks, or wall calendars).
- Please do not publish photos of personal data (e.g. patient number, ID stickers, hospital documentation, or any specific information about the donor).

Photo & Video Tips

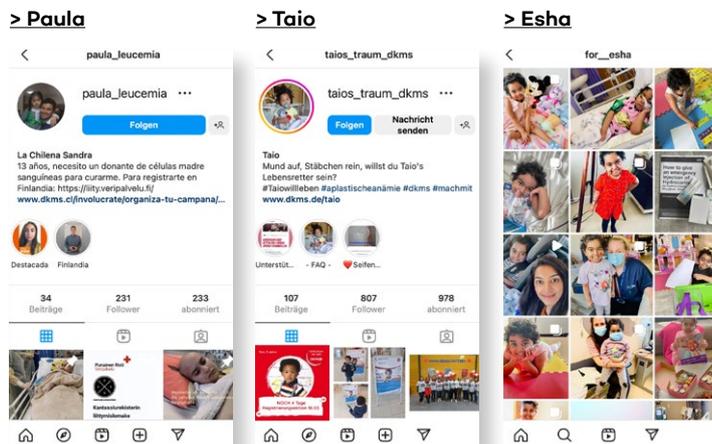
- Close and centered: Please try to get as much light as possible and ensure you are in focus. If other people are also in the picture, ask for permission.
- Originals without filters: If we ask for your photos to share on the DKMS social accounts, please send us the original images at full dimensions (without filters)
- The more, the better: Show a variety of yourself from before the diagnosis till your time in therapy. You can also make videos out of a compilation of pictures.
- Mix it up: Take a selection of photos and videos both vertically and horizontally, with and without flash.
- High resolution: If possible, try and send us photos and videos with the highest resolution you can get.
- If you want to use a DKMS Logo or branding, please contact us.

Little Help

Instagram:

- Share as many pictures as you can.
- Tag the DKMS with [\[@dkms_de\]](#) in your posts.
- In Instagram Stories, you can link to your Virtual Drive using the link sticker.
- With videos, you can make your Instagram Story even more authentic and better at connecting with your community.
- Produce Reels to reach out to new audiences.

Get inspirations here:



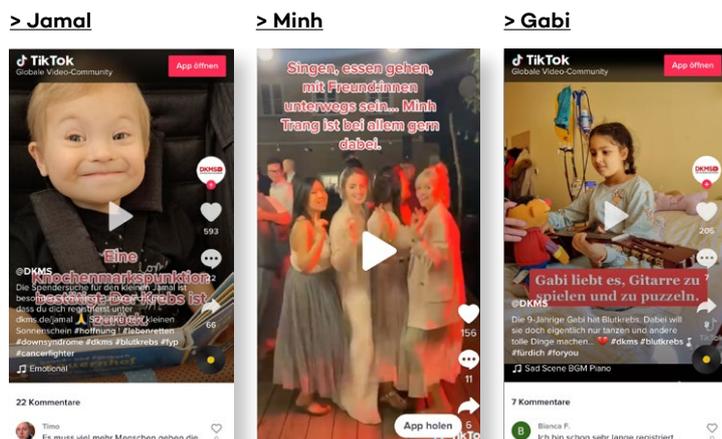
Facebook:

- Add the link to your Virtual Drive to every post.
- Tag DKMS with [\[@DKMS.de\]](#) in your posts.

TikTok:

- Tag DKMS in your videos with [@dkms_de](#).
- Tell your story as a video or use photos with the voice-over feature.

Get inspirations here:





WE DELETE BLOOD CANCER

Giving an interview or have further questions?

Thank you for supporting us and spreading our message. Please contact us if you receive an interview request so we can help you prepare and ensure you have all the information you might need. The main contact person before and during transplantation is your donor recruiter.

Unsure if your social media post meets the guidelines? Our social media team will be happy to help you and will often share posts on our DKMS channels. To do so, contact [\[social@dkms.de\]](mailto:social@dkms.de). In addition, our social media team is always happy to receive your photos or videos to share on DKMS' own channels.

You can find us here:

