

For Patients

DKMS Communication Guide

Introduction

First of all – thank you for being willing to share your story. ❤️

Your story is deeply personal, yet also powerful. When you share your experience with blood cancer, you give others a face and a reason to take action. Every post, video, media coverage, or word can inspire people to register as potential stem cell donors – and maybe even save a life.

At DKMS, we are deeply grateful to every patient and initiative group that chooses to share their journey publicly. 🙏 We understand that sharing your journey is not always easy. These guidelines are designed to help you tell your story in a way that is both authentic and safe, while protecting your privacy and that of the donor.

Telling Your Story

We truly appreciate that you are willing to share your journey. To protect both you and the donor, please keep the following in mind:

Privacy Notice

National and international regulations require anonymity between donors and patients for a specific period of time – sometimes permanently. This protects both sides and allows them to recover and make decisions free from emotional pressure.

Important: even small hints in texts and pictures – a hospital name, a date, a region – can unintentionally identify a person.

When sharing your experience, please follow these guidelines:

 Do share	 Don't share
Your story, emotions, and motivation	Exact dates of your transplant or hospital stay
General information about the donor (e.g. "a donor in another country")	Specific donor details (name, age, gender, city)
How DKMS supports you and why this mission matters	The specific name or location of the hospital
Your name, country and age, hobbies, passions, and dreams	Personal data such as address, birthdate, or ID numbers
Photos or videos that focus on you and your journey	Photos showing labels, documents, or hospital logos

Need inspiration? Here are some questions to get you started:

- What was your life like before your diagnosis?
- What went through your mind when you were diagnosed?
- What gives you strength during treatment?
- Why is a stem cell donation so important to you?
- What do you wish for your future?
- What message do you have for people thinking about registering as donors?

It can also be powerful to share milestones along the way:

- 👉 "Donor found!"
- 👉 "Day Zero" (the day of your transplant) – but please do not include the exact date
- 👉 "One year later – still fighting, still smiling."

These moments give hope to others and make your story relatable.

Photos & Videos – Bringing Your Story to Life

Images and videos are one of the most effective ways to connect with people emotionally. They show your courage, your personality, and your journey.

Tips for powerful and safe visuals:

- 📷 Focus on you: Show yourself clearly, in good light and with an authentic surrounding.
- 📽 Mix it up: Combine portraits, family moments, and treatment updates – photos as well as videos.
- 🗂 Keep it safe: Avoid visible documents like your ID, GRID number, name tags, faces of others, or dates.
- ✨ No filters needed: Authenticity is always more inspiring than perfection.
- 🤖 Keep it authentic: Whenever possible, use real photos and videos rather than visuals created or significantly modified with AI to help maintain trust and the credibility of your story. If you do use such content, please clearly label it as AI-generated or AI-modified and let us know when submitting it to DKMS.
- 📧 High quality: If you'd like us to share your content, please send us the originals (full resolution).

Sharing on Social Media

Every platform works a little differently. Here are some quick tips to help you reach the right audience:

Platform	Tips
Instagram	• Tag @dkms and add your virtual drive link via sticker, if applicable • Use reels or stories to reach new audiences
Facebook	• Include your virtual drive link, if applicable • Tag DKMS @DKMS to connect your post with the community
TikTok	• Tell your story in a short video or with a voice-over • Tag @dkms and use hashtags like #DeleteBloodCancer #DKMS
LinkedIn / YouTube	• Tag @DKMS to connect your post with the wider community

Use hashtags: #DeleteBloodCancer #DKMS #Hope

We are always happy to receive your photos and videos to feature on our DKMS channels. Together, we can reach even more people. 🌍

Questions or Interview Requests?

You don't have to handle it alone. If you are unsure whether your post follows these guidelines, or if you receive an interview request, please contact us before responding. We are happy to help you prepare and ensure your story is told safely and meaningfully.

✉ globalcomms@dkms.org

Final Thought

Your voice has power. By sharing your journey with courage and care, you not only raise awareness – you give hope. And hope is where every life-saving story begins. ❤️