

Guidelines for The SCAGO WhatsApp Forum

Description

A patient-centred online network created to support the primary sickle cell disease community globally (individuals living with SCD, their families and patient organizations).

Objectives

- Empower and educate patients and families on various topics including tips on managing sickle cell disease (SCD), clinical trials and research studies
- Build awareness and increase the level of knowledge/understanding of SCD among people of all ages and backgrounds, wherever they reside
- Determine the educational and support needs of those living with SCD, their caregivers and patient organizations
- Connect families with SCD to the patient organizations in their localities
- Connect families to one another
- Reduce stigma and discrimination experienced by persons living with SCD all over the world.

Who can join?

- People living with SCD
- Families, caregivers, friends and co-workers of people living with SCD
- Patient organizations
- Advocates and volunteers of the SCD community

What can be shared on the forum?

- Strictly SCD related news, stories and updates.
- All information to be shared must be vetted by at least one of the administrators of the forum. Proposed materials must be forwarded to at least one of the administrators a minimum of 72 hours before the intended posting date. Only approved materials may be posted.

Other rules of the forum

- The forum is not a political platform, no arguments or disrespect allowed.



- Ensure that you are posting accurate information, check your sources before you share.
- Never EVER use the forum to berate someone else or air grievances. If you have an issue, address it with the relevant person outside of the forum.
- The forum cannot be used to promote personal business.
- Only drugs approved by Health Canada and other National health agencies may be promoted.

Topics

We may invite care providers, patients and families to address and lead some of the discussions on the forum.

Consequences of non-adherence

Two warnings will be followed by removal from the forum.

Tips to reduce frustration around too many notifications

If you think you are receiving too many notifications, you may hit “Mute” on the WhatsApp forum. You will still receive all the messages, but your phone will not send you a notification when there are forum updates.

