

# OPEN versus CLOSED Social Networking Groups



Cheryl Nineff D'Ambrosio  
Founder, President of MyGirlsBlood



## Objectives

The discussion of topics related to girls and women with bleeding disorders (WWBD) are still in an infancy state. Spanning the spectrum of research, diagnosis, treatment and the need to improve the quality of life for WWBD, continued progress requires ongoing awareness.

Awareness brings interest which creates desire that can turn into action.

## Methods

MyGirlsBlood is an open facebook group to serve girls and women with bleeding disorders worldwide and those who care for them.

Topics are posted by a group member, or a moderator.

## Results

Topics during 2013 included:

Toddlers with face bruising, carriers who bleed, herbal products, IUDs, pregnancy induced factor 8 acquired hemophilia, anatomy of a woman's vagina, FGM, myositis ossificans, pregnancy and childbirth questions, best practices for menorrhagia, preference of sanitary products in developing countries, a young girl facing eye surgery, men helping women in the hemophilia community, home schooling for girl bleeders, and dealing with stigma from family for a young woman who may need a hysterectomy.



## Conclusions

Having closed social networks are needed for groups that need privacy and security in their communications. WWBD need privacy to learn from one another and to solve intimate problems.

However, when there are only closed groups, awareness ceases to exist across the larger multi-disciplinary and diverse worldwide community.

Many would like to help, but would not be permitted in a closed group for WWBD. When those outside a closed group have no mechanism to identify or understand what needs to be studied, treated or for which topics funds must be raised, they will put their efforts and dollars into other causes.

Simply put, it's so much easier to understand, to improve and to manage something that isn't a secret.

### REFERENCES

Facebook group - MyGirlsBlood Discussion Group May 2011

Layout by: Iman Rasheed (imanshd@gmail.com)

