



### Ambassadors for MyGirlsBlood

*From top: 1st row:* Nabila Husseni (Ahmedabad, India), Dr. Shahla T. Sohail (Lahore, Pakistan), Andrea Trinidad Echavez (Manila, Philippines), Brittany Zellner (Wisconsin, United States),  
*2nd row:* Blanca Ramirez and Cynthia Ramirez (Texas, USA), Shirin Ravanbod (Tehran, Iran), Barbara Forss (Washington, USA),  
*3rd row:* Milena Pirnat (Winnipeg, Canada), Moline Odwar (Nairobi, Kenya), Ryanne McIsaac (Alberta, Canada), Darcy Zwier (Wisconsin, USA),  
*4th row:* Chloe Christos (Perth, Australia)

# Women With Bleeding and Leadership - A Wicked Problem?

*Cheryl D'Ambrosio (USA) with Carol Nave (USA), Nabila Husseni (India), Andrea Trinidad Echavez (Philippines), Moline Odwar (Kenya), Barb Forss (USA), Brittany Zellner (USA)*

### Introduction and Objectives:

How do women with bleeding fit into our worldwide leadership programs?

According to Wikipedia, a wicked problem is one that is impossible to solve because of incomplete, contradictory, and changing requirements that are often difficult to recognize.

Women with bleeding often don't want to talk about their issues due to embarrassment, stigma, and shame. Less developed countries do not value women and this makes their problems easier to ignore. As a result, there are currently few women with bleeding in leadership at the Chapter or National levels making it more difficult to achieve a position at the Global level.

### Materials and Methods:

MyGirlsBlood launched a collection of surveys in 2015 using several social networking groups. The intent was to neutralize the thinking that we have insolvable problem by gathering data to begin to understand women's needs, issues, capabilities and preferences.

### Results:

Seventy-five women with bleeding issues participated from: Pakistan, USA, Macedonia, Australia, Denmark, Nigeria, Philippines, Canada, Kenya, Iran, Chile, Uruguay, Malaysia, Serbia and India. Bleeding disorders reported (some have more than one): vWD (29), mild hemophilia (16), Glanzmann's thrombasthenia (2), ITP (2), not yet diagnosed (0), F I (3), F V (6), F VII (1), F VIII (14), F IX (4), F X (1), FXI (3), FXIII (1).

Survey showed that these women range from 30 minutes to 5 hours per day using social media to learn about bleeding disorders and connect with other women in the worldwide hemophilia community.

At a local level, they indicate that when women are grouped together, the needs of women bleeders are rarely addressed. Most of the focus is on the role of a mother of a bleeder. And, at a national level, they felt the focus was on women being a parent vs. being a patient.

### Conclusions:

Helping more women get tested, conducting local and national surveys and developing partnerships with organizations who train women in leadership will raise the potential leadership opportunities for women with bleeding. Together, we will find that these problems may not be so wicked after all.



Poster  
Presented at:

DOI: 10.3232/psa.ea.WFH2016.2016

Capacity Building  
Cheryl D'Ambrosio

38-PP-W  
WFH2016

WFH2016

WFH2016