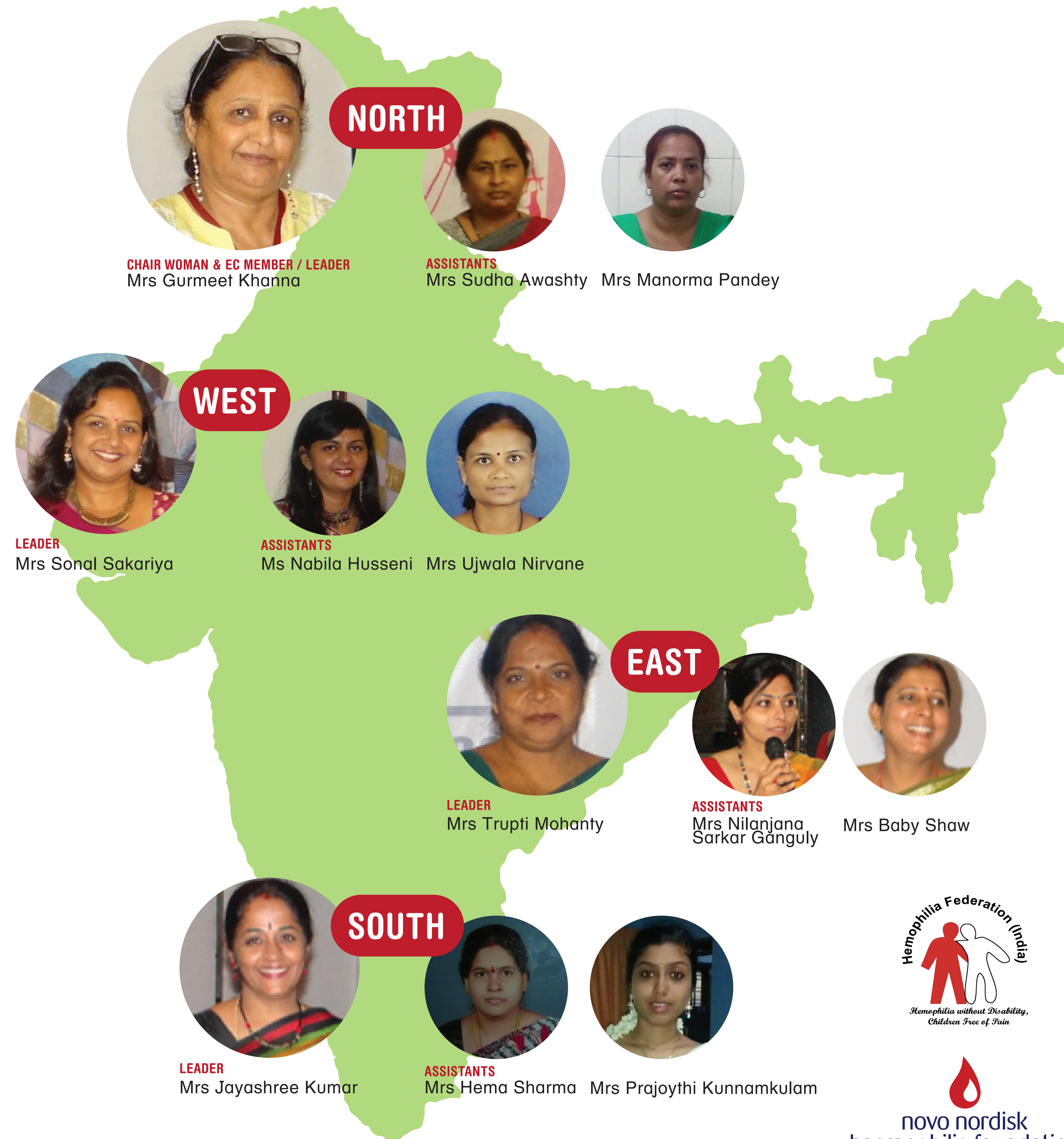




Women's Group Leaders Hemophilia Federation

Capacity Building in India - Integrating Women Into the Picture

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Introduction and Objectives:

With 1.2 billion people, India is the second most populous country in the world. And, we have very challenging logistics for anyone who needs to travel from one part of the country to the other.

Hemophilia Federation (India), an all-male organization, decided to develop a national women's group and bring together both women caregivers and women bleeders to create a platform to address the needs of women throughout their national bleeding disorder community.

Materials and Methods:

Beginning with a Master Training Programme, there were twelve women's workshops and a first-ever Annual General Meeting, held in many cities, over a 2- 1/2 year period. These served to provide both training and leadership opportunities to over 200 women.

Women's Topics included developing a leadership guide, presentations on empowerment, Indian laws, psychosocial needs, women and bleeding, and sharing ideas between them as caregivers.

Results:

These women are now seen as a vital part of the India hemophilia community. They are volunteers for World Hemophilia Day, presenters at workshops, coordinators for Continuing Medical Educational programs for their Chapter, publicists, reporters, and interpreters of the many Indian languages. They speak at workshops about their strengths of being a mother and a wife, and the pride they have in advocating for their family. Women who attend these workshops leave knowing they are not alone in their struggles.

Beyond working with women, they are now learning to work with men, meeting professional women, and meeting individuals from other countries who come to applaud their work.

Conclusions:

Hemophilia Federation (India) - a national men's hemophilia organization unselfishly and proudly stepped forward with a long term vision that the women in their community needed to find their voice, develop skills outside of their home, beyond that of a caregiver, in order to find ways to become empowered. These women are now celebrating their strengths and HFI is proud of the women and what they bring to their community.

