

Development of a hemophilia youth group in New Delhi through the Manitoba-Delhi Twinning partnership

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INTRODUCTION



The Hemophilia Society Delhi (HSD) recognized the need for a leadership succession plan to secure the future of the hemophilia community in the Delhi National Capital Region of India, and formed a youth group in February 2011 with a view to groom potential leaders. The award winning Winnipeg-New Delhi twinning partnership provided the required momentum to the youth group.

ACTION

In September 2012, HSD organized a youth group meeting as part of the Delhi-Manitoba twinning partnership under the mentorship of Dr. Jayson Stoffman. An interactive discussion with young persons with hemophilia (PWH) was held to consider the specific and unique issues faced by them and their role in the hemophilia community. The meeting provided motivation for the young PWH, and interest in establishing a youth

group increased.

The youth group started organizing regular meetings focusing on grooming youth as leaders, providing psychosocial support, advocacy and lobbying efforts, and brainstorming about steps to help support the hemophilia community. Among other events, the group organized a school awareness program and facilitated HSD during two "Walks for Hemophilia". The

group also conceptualized, designed, and organized a transitional educational program for teenaged PWH and their parents called "Generation Bridge".

Throughout this period, Dr. Stoffman kept communicating with the group to encourage them in their work. A follow-up mentoring session for the core team of the youth group was organized during the twinning activities of 2013.



RESULTS

The youth group of HSD has established a committed volunteer base and has become a source of potential future leadership. Youth group leaders are being groomed to be inducted as part of HSD's executive committee, and the activities of the youth group are having a positive impact on PWH and their families in the Delhi region.

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