

CAPACITY BUILDING AND LEADERSHIP INITIATIVE:

Bringing change by improving access to care and awareness

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Introduction & Objectives

The society in which we operate is relatively conservative which further creates several problems for the patients and their families, such as myths, misconceptions and stigmatization of the disease. Our main concern is to remove these artificial hurdles, as much as possible, so that patients can live in an environment that is conducive for having a progressive social identity. Pakistan Hemophilia Patients Welfare Society [PHPWS] is in a transition phase and is being revamped to face the various challenges of such progressive society. Consensus was developed around further empowering & upgrading the organization that is independent, sustainable and has the ability to respond to patient's needs. Hence, a large scale advocacy and awareness campaign was designed and implemented, which consisted of innovative initiatives.

Methods & Material

A comprehensive project in collaboration with NNHF was launched in order to boost the national drive of hemophilia in Pakistan. The below strategies were initiated to build a sustainable hemophilia response in the country:

- a) Build the capacity of PHPWS in order to make it an independent and sustainable patient's organization;
- b) Increase awareness in general public and medical community through innovative sensitization initiatives for the reduction of Stigma associated with Hemophilia;
- c) Develop a centralized web-based National Patients Registry;

Results

a) Through organizational development, this patient's driven national organization now holds the capacity for effective advocacy for the rights of the patient's community;

- b) By increasing awareness in general public through sensitization initiatives, stigma has reduced and access to the diagnosis & treatment enhanced;
- c) Initiated strategic information gathering for statistical analysis and understanding trend, which is critical in devising effective future strategies of the response.

Conclusions

The project gave enough oxygen to the hemophilia movement in Pakistan and equipped it to magnify all the good work that community is doing at the grass-root level to capture government attention. It further strengthened the organization to the core, and enabled it to effectively deal with various concerns, which is indicative of enhanced capacity. Collaboration with medical community enhanced and development of Patients Registry has improved the decision making process.



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Quality of Life
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