



# POSITIVE DIARIES:

## Testimonials of people living with bleeding disorders in Pakistan

MASOOD FAREED MALIK

### Introduction & Objectives:

In view of the stigma and discrimination associated with Hemophilia and allied bleeding disorders in a conservative society like Pakistan, a strong need for sensitization was identified. We've been observing that, whenever a patient was diagnosed with Hemophilia, ample counselling was required on psycho-social aspects, to help them understand, that it is not a death sentence. Otherwise, everyone had a frightening perception of the disease. Hence, a community testimonial's collection initiative was taken to highlight the lives of people living with bleeding disorder, emphasizing that they have come a way long, and have ultimately survived despite multiple complications and as well as with serious socio-economic circumstances.

### Methods & Materials

It was extremely tough to convince the patients to share their stories as they are reluctant due to the societal pressures and thus hide their illness. Therefore, peer-interviewing approach was adopted as it would help the patients to develop a sense of relativity. At first, they were counseled that the initiative tends to reduce those societal pressures and will eventually empower the community to have their own identity, confronting the stigma.

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### Results

The Pakistan Hemophilia Patients Welfare Society [PHPWS] revitalize the lives, which was then dominated by depression and traumatizing fear. It has instilled a feeling of bravery and valor that if those people can be at that point with such pain and sufferings, then we must also do something for them. For the first time in this country, these people felt so empowered to share their stories on disease-related stigma and expressed their courage, inspirations, concerns and determination to trigger change in the society. The initiative has resulted in a significant reduction of the negative perception of disease.

### Conclusions

It is also a measure of organization's success, that years of work and advocacy did sensitized the community and have empowered them to reveal their, aspiration and concerns. Positive Diaries, a NNHF's funded project, is a view into the lives of people with Hemophilia in Pakistan. We consider it critical to bring a greater understanding of the complex socio-cultural factors that have contributed to the lives of these patients.

