



## Organising people with haemophilia in India

### Lessons learned

It is possible to diagnose and organise a large number of people sharing a relatively rare diagnosis like haemophilia (blood coagulation disorder).

Patients' organisations can educate health personnel about their condition and be advocates for health planners to incorporate their concerns.

The balance between expanding possibilities for diagnosis and for access to expensive prevention and treatment needs to be planned for and monitored.



Photo: Dorte Lysgaard/Danish Haemophilia Society  
One of the boys in this family has had so many bleedings in his left knee, that he can no longer stretch his leg

### Background

In any population about 1 in 5000 men suffer from haemophilia in various degrees of severity. According to a global survey from 2002 by the World Federation of Haemophilia between 80 and 95% of the afflicted are diagnosed in developed countries. In Bangladesh, Indonesia and China only 2-5% of cases are diagnosed, but in India up to 12% of cases are diagnosed. It is estimated that there are about 50.000 persons with severe haemophilia in India. The Indian Ministry of Health does not include haemophilia in its programmes, and medicine is not available in hospitals or subsidized.

Prevention and treatment of bleeding is done with various types of medical products known as factor, cryo and plasma. This medicine can be very expensive by local standards, and is often only used for treatment. Furthermore, physiotherapy can prevent permanent disabilities from bleeding in the joints.

**Location:**

India

**Title:**

Living with Haemophilia in India

**Year of implementation:**

1998-2003 (phase II from 2004-2006)

**Funding:**

DKK 10.472.208 (USD 1,7 mill) for phase I channelled from Danida through The Danish Haemophilia Society

### Objectives of the project

- To improve the organisational capacity of the Haemophilia Federation India at the federal, regional and local levels to take care of the interests of people with haemophilia in India
- Provide access to diagnosis, treatment, information, education and counselling for 8000 persons with haemophilia as against the 4500 receiving treatment at the initiation of the project.
- Provide access to information on carrier detection, prenatal diagnosis and counselling services to carriers and their families in order to minimize stigmatisation.

### Results after the first four years

#### Organisation

- 4 regional offices have been established.
- 27 local offices have been established.

#### Diagnosis

- 5000 persons with haemophilia have been diagnosed apart from the nearly 4000 people who were already identified.
- 26 laboratories have been established.

#### Treatment

- 50 doctors have been trained.
  - 26 treatment facilities have been established.
  - 33 physiotherapists have been trained.
  - 57 laboratory technicians have been trained.
- All local offices have referral links for care delivery with government or private clinics.



## Results continued...

### Information

- Newsletters in 10 local languages.
- Development and production of basic information materials for persons with haemophilia.

Development and production of basic information materials for medical personnel.

### Children and parents

- Youth groups are established
- Parents' meetings have been held
- 31 summer camps have been held for 600 children

Furthermore, the Indian Haemophilia Federation has an agreement with some foreign pharmaceutical companies that they will get products, which are near expiry date, for free or with a discount.

### Main activities included

- Production of posters, leaflets, newspaper articles, radio programmes and other media informing about haemophilia.
- Forming new local offices.
- Formulation of an organisational development plan, an information policy, and a long term donor policy.
- Advocacy and lobbying.
- International and local fundraising campaigns.
- Training of staff in lobbying, management, information and communication.
- Training of medical personnel and laboratory technicians.
- Quality control procedure established for laboratories.

### Other lessons learned

- It has taken time to foster an environment where people with haemophilia and their families appreciate activities that are not directly related to fundraising and procurement of factor.
- It is still a challenge to get mothers' groups on track even though it is obvious that mothers

have many shared concerns. Particularly the poorest women are difficult to include. Some mothers' groups have – on their own initiative – turned themselves into producers of crafts for sale instead. This form of organisation has been successful and still offers mothers space to share their situation with each other.

- When selecting new areas for establishing chapters of the Federation success depends on the dynamics of the local volunteer base, which should be assessed together with access to a medical institution willing to deliver care.
- Carrier detection and sharing of information about prenatal diagnosis, procedure and costs has been a challenge, which takes time to overcome. Formal ties with institutions that can provide the diagnosis and counselling is needed as well as economic support for travel, accommodation and tests for women seeking advice.

### Applying for phase II

The Danish Haemophilia Society applied to Danida for a phase II aiming to consolidate results and build sustainability into the structures already established. Danida allocated Euro 448,368 for phase II from 2004-2006.



Photo: Dorthe Lysgaard/Danish Haemophilia Society

### Further Reading:

Contact the Danish Haemophilia Society for more information: [www.bloderforeningen.dk](http://www.bloderforeningen.dk)

**Haemophilia Federation (India)**  
<http://www.hemophiliaindia.net>

**Danish Council of Organisations of Disabled People** [www.disability.dk](http://www.disability.dk)

**Danida File:**  
104.N.404.f