

## At a glance

Certificate No: PCP-2005/0034

### Registration

The Voluntary Social Welfare Agencies (Registration & Control) Ordinance, 1961 (Registration No DDSW&WD-LD/ 97-1011) on 05 March, 1997 in Lahore

### Major Programmes

Medical care of haemophilia patients

### Human Resource

Governing Body: 15 members

President: Dr. Shehla T. Sohail

Staff Strength: 03 (2 Males, 1 Female)

### Area of Operation

Punjab (Lahore)

### Banks

Habib Bank Ltd, Lahore

### Auditors

Aftab Nabi & Co. Chartered Accountants, Lahore

### Tax Status

Exempt U/S 2(36) of the Income Tax Ordinance, 2001

### For Information and Donations

10-Jail Road, Inside Gulshan Carpet Building, Lahore.

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Email: [hpws@wol.net.pk](mailto:hpws@wol.net.pk)

## Mission

To provide complete medical care to haemophilic patients



## Understanding Haemophilia

Haemophilia is the deficiency of a clotting factor in the blood that causes a person to bleed uncontrollably from injuries. The slight bleeding that causes bruising does not always stop. This can result in swelling and intense pain. Repeated bleeding can leave a person permanently crippled. A disease like haemophilia is largely associated with men. Approximately one man out of every four thousand in Pakistan inherits Haemophilia from his mother. The disease has no cure and the treatment is limited and expensive. Even the simplest surgical procedure could prove fatal for such patients due to excessive and unstoppable bleeding. The alternative, surgery involving a regular and almost unlimited supply of factors, is an expensive procedure.

Earlier, patients suffering from this disease followed a different procedure where they were injected with plasma to cover the deficiency caused by any particular factor. The cost was enormous depending upon the nature of bleeding. Prior to 1997, there was no screening facility in Pakistan to assess whether the injected plasma contained any virus or not. With technological advances, the system of injecting plasma was changed and replaced with the injection of concentrated relevant blood factors. The factors are now screened at the laboratories and therefore contain no other viral disease.

Factors needed to stop bleeding are injected with continuous frequency: one injection costs Rs. 3,500 and in one surgery 20-30 injections are normally used. Despite being afflicted with this terrible disease, haemophilic patients can lead a normal life if he/ she is provided with supportive treatment and the underlying fact is that the supportive treatment is very expensive and few can afford it.

## Inception

As haemophilia is a rare disease throughout the world, the treatment is limited and expensive. In most parts of the world, patients have formed their own haemophilic care societies.



The Haemophilia Patients Welfare Society was set up in 1998 by a group of doctors with support from Bayer International, a pharmaceutical company which produces and supplies medicines to Pakistan. The doctors agreed to set up and register the Haemophilia Society in Lahore. In 2000, the society was registered with the World Haemophilia Federation. A medical advisory board was formed which consisted of highly qualified surgeons and specialists in the field of haemophilia and pathology. In 1998, Dr. Shehla Sohail, a child specialist, assumed charge of the society.

HPWS aims to provide comprehensive care to people suffering from haemophilia and to unite them into a community motivated for self-help and mutual support. In addition, HPWS offers educational, financial and medical assistance and pays for patients who cannot afford treatment.

#### Outreach

The society has 248 registered patients from Punjab alone. To cater to the needs of far flung areas of Punjab, the society has established two branches, one in Multan and one in Sambaryal Tehsil in District Sialkot. Independent chapters in Karachi and Islamabad are operational since the 1980s. Provincial chapters are also being set up in Peshawar and Quetta.

#### The Facility

The society works from one room donated by Chughtai Laboratories. Patients are registered with the society and all tests are performed in the Chughtai Laboratories. All procedures involving injecting or operating, are performed on the premises. A duly qualified nurse is available at all hours. Most patients are admitted to the Ammar Hospital, a private facility. Since most of the patients belong to the middle and lower middle class, care and treatment is subsidised for haemophilia patients at these facilities.

“ Thank you for  
bringing hope, health  
and healing to our  
children ”

Father of a patient

### Income and Sources of Funding (Rs.)

Sources of funds	2003	2004	2005
Self Generated Income	34,900	12,569	92,250
National (Grants/ Donations)	634,460	173,400	197,664
International (Grants/ Donations)	1,336,865	1,682,341	1,310,520
Total	2,006,225	1,868,310	1,600,434