



# ANNUAL REPORT

## 2019

A YEAR OF SUCCESSFULLY  
OVERCOMING CHALLENGES

**HEMOPHILIA**  
PATIENTS WELFARE SOCIETY  
RAWALPINDI CHAPTER





## President

### Dr. Munawar Sher Khan

Another year and another exciting report but first I want to thank all those who supported us through 2019 with their prayers and donations, both in kind, money and time. Without you we couldn't have coped with the many challenges that we had to face in the year. 2019 started with a bang as our nationwide project "Caring for the Uncared" was accepted by the World Federation of Haemophilia which meant reaching out to around 500 PWBD from those 16000 or so diagnosed hemophiliacs who were not receiving the care they deserved and were just a statistic in the books. Linked with the other HPWS Chapters under the HFP – NMO umbrella I was certain we would not only manage this project but also realize some of our dreams from 2018 as well, but that was not to be as we had to cancel meetings, seminars and out station visits time after time with the sudden breakdown in the law and order situation resulting in mayhem and deaths too. However you will see from the following pages that we faced these challenges with equanimity and overcame many of them. Look forward to 2020 and with your support, to an even more successful year.

## Director HTC Dr. Tahira Zafar



Our Haemophilia Treatment Centre (HTC) has been on the fore front of caring for the haemophilia community since its inception in the nineties. Over the years our dedicated clinical team has worked hard to make it a centre of excellence with local, national & international collaborations. This year our special focus has been to update the knowledge & skills of our staff and share it with haemophilia care givers so that our patients are looked after well where ever they happen to attend for treatment. The highlight in 2019 has been the implementation of prophylaxis for our children which has been achieved due to collaboration between the Humanitarian Aid Program (HAP) of World Federation of Haemophilia(WFH), the Haemophilia Foundation of Pakistan (HFP), Haemophilia Patients Welfare Society Rawalpindi (HPWS Rwp) , the staff of the Haemophilia Treatment Centre (HTC) and our patients & their parents who have put in their share to make it a success! We have started a number of projects to further impact lives of our patients and look forward to a brighter future for the haemophilia community as we go along.

## **A ray of hope for the haemophilia community!!**

The **main Mission of HPWS Rwp** is to provide quality treatment to patients with Inherited bleeding disorders and help them develop as normal individuals & useful members of the Society .This is achieved through its Haemophilia Treatment Centre (HTC) .

The **Haemophilia Treatment Centre (HTC)** of HPWS Rawalpindi is an outpatient facility which looks after all the medical needs of the Haemophilia community by its well-trained Medical & Nursing staff (Medical officer, nurses, and consultants). It has a comprehensive Medical Advisory Board with specialists covering all aspects of Inherited Bleeding Disorders who volunteer free services to the patients. The indoor treatment facilities are provided by a network of Haemophilia Friendly Hospitals(HFH's) in the twin cities of Rawalpindi & Islamabad.



## **Services provided by the HTC**

- Free check up by the MO free consultation & check up by the consultants at HTC, if required
- Free / subsidized treatment (as per Policy)
- Free treatment for patients on Low Dose Prophylaxis (LDP)
- Free Referrals to & consultations by our Medical Advisory Board (MAB) & relevant Doctors at Haemophilia Friendly Hospitals (HFH's), if required
- Admission in HFH if required
- 24 hr on call service for emergencies
- Subsidized emergency care per policy
- Free physiotherapy sessions
- Free counseling
- Free training to prepare Factors
- Free training to infuse Factors
- Access and invitation to Awareness activities, Seminars, Workshops

# Patient Registration at HTC

- Total registered patients in 2018: 1042
- New Patients in 2019: 75
- Total registered patients in 2019: 1117

HTC Rawalpindi				
Total Patients			1117	
Males = 941			Females = 176	
Sr. #	Diagnosis	Number of Patients	Diagnosis	Number of Patients
1	FVIII	639	vWD	94
2	FIX	123	GT	36
3	vWD	86	FV	9
4	GT	25	FVII	8
5	FVII	19	Fx	7
6	FV	9	FXIII	5
7	FXIII	9	BSS	1
8	FX	6	SPD	1
9	BSS	1	FI	1
10	SPD	1	FIX	1
11	Un Diagnosed	23	Un Diagnosed	13

vWD von Willebrand Disease  
SPD storage pool disease

GT Glanzmann's Thromboasthenia  
BSS Bernard Soulier Syndrome

## Patient Visits:

Out Patients	2385
Low Dose Prophylaxis	780
• <b>Total OPD visits</b>	<b>2385</b>
○ New registration	75
○ Admissions	51
○ Referrals	83
○ Bleeds	2176

Patient Attendance 2019								
Total Patients 539	<b>Males</b>							
	FVIII	FIX	VWD	G.T	FV	FVII	FXIII	Un Diag.
Male 482	365	69	34	4	1	8	Nil	1
Female 57	<b>Females</b>							
	FVIII	FIX	VWD	G.T	FV	FVII	FXIII	Un Diag.
	Nil	1	41	8	1	5	1	Nil

## Factors used for treating the patients

Factor consumption 2019			
Factors	Units	Total patients	Average IU per patient
FVIII (OPD)	<b>1243250</b>	365	3406 IU
FVIII (LDP)	<b>258750</b>	14	18482 IU
FIX	<b>295,500</b>	70	4221 IU
VWF	<b>325,300</b>	75	4337 IU
FVII	<b>547,200</b>	25 (FVII & G.T)	21888 IU
FEIBA	<b>67,000</b>	4	16750 IU

## Surgeries

Many successful surgeries were done, during the year , on our patients. They were done at the Haemophilia Friendly Hospitals with proper protocol from the HTC and factor support by HPWS.

Sr. #	Operation / Procedure	Comments
1	Scrotal Hernia	(successful)
2	Intramedullary nail fixation of Tibia	(successful)
3	Appendectomy ( 3 )	(successful)
4	Circumcision (2 cases)	(successful)
5	Delivery (FXIII def.)	(successful Normal delivery)
6	Circumcisions (6 )	(successful) WFH Project for surgeries
7	Removal of renal stone	(successful)
8	Operative Laparoscopy of Hemorrhagic Cyst	(successful)
9	C- Section (VWD) ( 2 )	1 successful, 1death on 3 <sup>rd</sup> day of Section

# Success Stories

## A successful major operation Factor VII deficiency

Haemorrhagic ovarian cyst removal with advice & treatment support from the centre.



## Happy ending for life threatening bleeding F IX Deficiency

This 5 year old patient developed Intracranial bleeding after fall. He was treated at the HTC and referred immediately to CMH Rawalpindi , where he underwent emergency surgery for removal of the brain haematoma. The HTC provided full factor cover protocol and factors.



## **A difficult circumcision Haemophilia A with Inhibitor**

Admitted in Holy Family Hospital Rawalpindi for planned circumcision. He was operated and was stable for four days after which he had repeated episodes of bleeding from site of operation. The bleeding site was re stitched again. He remained under treatment in Hospital for one month. During his stay in Hospital he was provided complete Factors coverage. He was given FEIBA and rFVIIa.



## **WHAT A MIRACLE !! A PATIENT WITH A SEVERE, INHERITED BLEEDING DISORDER**

### **VWD TYPE 3 DELIVERS NORMALLY**

A female patient of ours was admitted in Pakistan Institute of Medical Sciences (PIMS) Islamabad, Pakistan for planned C-Section. Complete VWF haemostatic cover plan & vWD Factors were provided . She give birth to a healthy baby girl without any complications



## PROJECTS RUN BY THE HTC

HCV treatment: HCV positive patients are referred to Dr Nadeem Ikram , Consultant Haematologist at Benazir Bhutto Hospital (BBH) Rawalpindi, who coordinates their investigations and treatment



## TRAINING OF PATIENTS & PARENTS TO PREPARE & INFUSE FACTORS

Majority of adult patients and parents are trained to prepare and infuse the Factors. It is one of the most important tasks of HTC so that patients can infuse themselves at home if they have bleeds and cannot come to the HTC. Training is provided by HTC Coordinator.



**Mother of a patient infusing factor**



**Father of a patient infusing factor**

# LOW DOSE PROPHYLAXIS - UPDATE



In developed countries Haemophiliac's routinely receive factors, as prophylaxis to prevent bleeding by keeping the factor level above 1% at all times. This prophylactic use of factors is helpful in decreasing /preventing bleeding episodes into joints thus improving joint health and preventing deformities. The dose of factor VIII or IX is 20 to 40 IU/kg body weight given twice a week.

However this is a very expensive option and not possible in developing nations. World Federation of Hemophilia (WFH) supports patients in such nations – including ours, under their Humanitarian Aid Program by providing factor donations for prophylactic treatment. Presently we have 14 patients (1-8 years) out of which 7 are given 250 IU's twice a week (Group A) and 7 are given 250 IU's once a week (Group B). Groups are made on the basis of weight and bleeding frequency.

We are looking forward to add 10 more patients in the following year.

## WOMEN WITH BLEEDING DISORDERS

176 females with inherited bleeding disorders are registered at the HTC, majority (53%) having severe von Willebrand disease. Their main problem is heavy menstrual bleeding

### FEMALES REGISTERED AT THE CENTRE

Females = 176	
Diagnosis	Number of Patients
VWD	94
G.T	36
FVII deficiency	8
FX deficiency	7
FV deficiency	9
FXIII deficiency	5
BSS	1
SPD	1
F1 deficiency	1
Un Diagnosed	13
<b>FIX</b> deficiency	<b>1</b>
<b>Total</b>	<b>176</b>

### SURGERIES/DELIVERIES & OUTCOME

#### VWD C- Section = 02

- Operated at PIMS Islamabad with full haemostatic cover. NO complications
- A patient of Holy Family Hospital, operated without surgical protocol. After 3 days of operation she was registered at HTC Rawalpindi. Factors were provided but unfortunately she died because of excessive bleeding.

#### FXIII Normal Delivery = 01

Under FFP cover , gave birth to a healthy baby girl. No complications.

#### F VII deficiency laparoscopic removal of Haemorrhagic ovarian cyst.

Successful removal without any complications

## **EDUCATIONAL & AWARENESS ,CAPACITY BUILDING & PSYCHOSOCIAL ISSUES FOR FEMALES**

Regular meetings and workshops are carried out for counseling and increasing their awareness about their disease



## **HIFAZAT E NAJAM Treatment Support Project July 2019**

Hifazat e Najam Treatment Support Project will help those Persons With Inherited Bleeding Disorders (PWBD) , registered with the Haemophilia Patients Welfare Society, Rawalpindi (HPWS- Rwp) , who cannot afford to pay for Factors obtained from the market i.e. income is below Rs. 30,000.00 per month, with preference being given to those who have 2 or more PWBD to support, have a moderate to severe deficiency and in particular those with VWD, FIX and FVII deficiencies particular those with VWD, FIX and FVII deficiencies.



## Hifazat e Jan Project

A project for saving lives of patients with Inherited Bleeding Disorders who have life threatening bleeding:

- Intracranial bleed
- Massive injury
- GIT bleed
- Throat bleed
- Menorrhagia – Massive
- Intra & Post Partum Hemorrhage
- Post major surgery

## CONTINUING MEDICAL EDUCATION(CME)

Regular educational activities are carried out at the HTC to increase the knowledge & practical skills of health care professionals in looking after patients with inherited bleeding disorders.



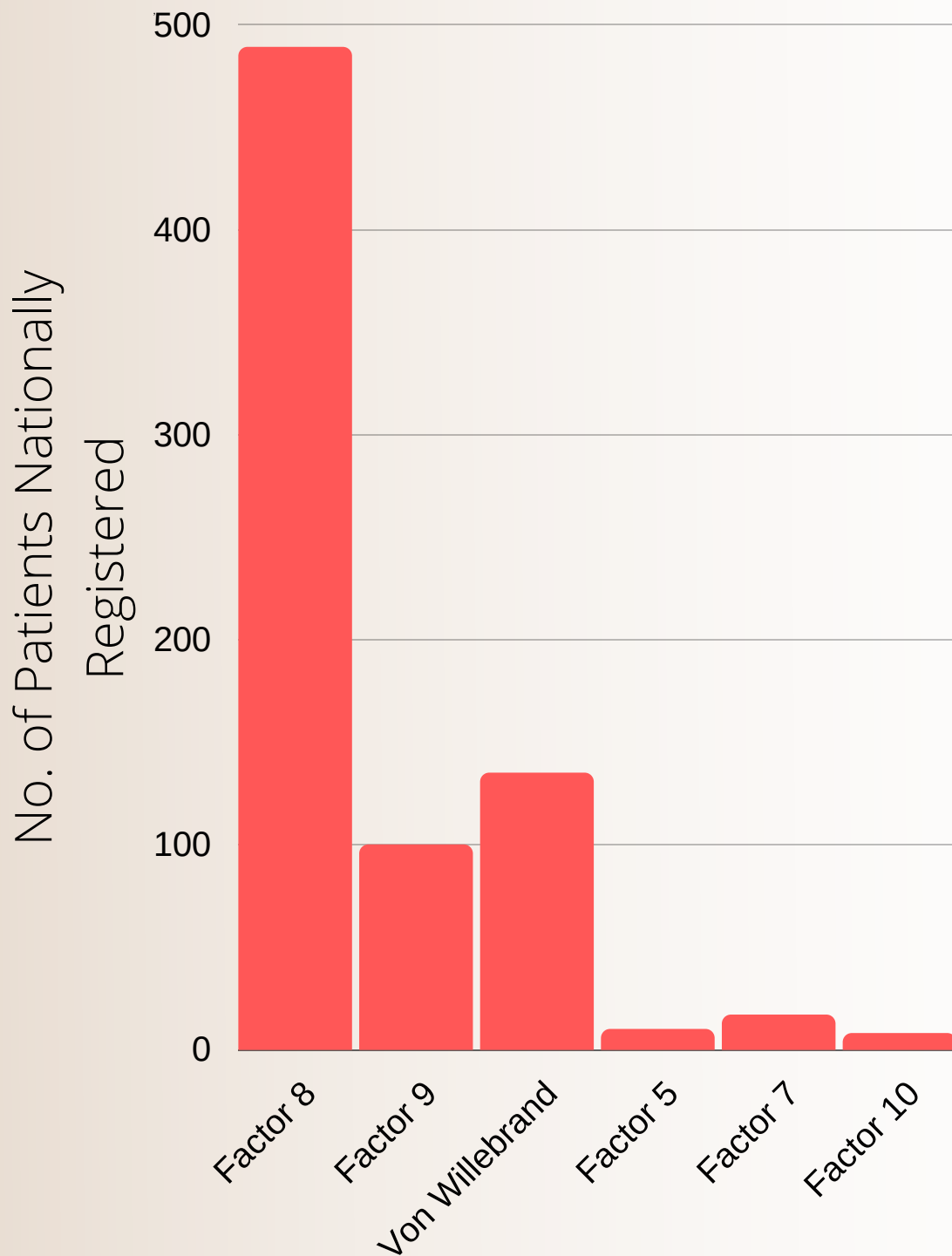


## Interaction with patients & families

The HTC staff interacts very closely with the patients & their families. This has led to a friendly atmosphere making the patients very comfortable.



## Nationally Registered Patients with Haemophilia Foundation of Pakistan (HFP)



## Adult HTC at PIMS



The HTC at the Children Hospital under the able care of Dr. Tazeen has been providing facilities to patients since 2005 to both children and adults. However over the years it became apparent that the children HTC facilities could not cope with the increasing burden of adult patients.

Dr. Zahida Ahmed ( Dental Surgeon and Member Medical Advisory Board ) due to her keen interest in pursuing the cause of Hemophilia , along with Dr Tahira Zafar was able to convince the PIMS administration to establish an Adult HTC and obtained special approval of ED PIMS, Dr Ansar Masood with facilitation by Dr Anjum Javeed (Director PIMS) & Dr Iqbal Durrani (Director Children Hospital) that an adult patients HTC was established at PIMS New Emergency on 14th September 2019.

Both Adult and Children HTCs collaborate very closely with the HTC of HPWS Rwp and share patient care. The Haemophilia community uses the inpatient facilities and transfusion of blood components while the OPD facilities help to lessen the burden of HTC Rawalpindi. Since there is provision of factor concentrates for emergencies only at both these centres, the rest of the patients who require factor concentrates or expert advice by the Haematology Consultants are referred to HTC Rawalpindi. These Centres also use all the protocols developed at HTC Rawalpindi and the consultant's advisory service.



# PROFESSIONAL MEETINGS/SEMINARS



Development of National Medicine Policy



Punjab Health Minister's - Dr. Yasmin Rashid's visit to HPWS Rwp



Workshop on Novel Therapies for the treatment of inhibitors - UAE



CME Meetings with staff and students

# MR. BRIAN O' MAHONY'S VISIT



WFH representative Mr. Brian O' Mahony arrived in Islamabad on a 04 days visit to Pakistan on 10th of October 2019. He was received at the airport by Dr. Munawar Sher Khan, President HPWS Rawalpindi and Mr. Masood Fareed Malik, President HFP. They met Dr Anjum Javeed, Joint Exec Director of PIMS and programme manager for all health projects for MOH & discussed need for adult facility at PIMS & procurement methods for CFCs. A PC-I for a Blood Disease Centre at PIMS was prepared in 2009 & the need for reactivation was also considered. There was a visit to HTC at children hospital PIMS Islamabad. A brief presentation was given by Prof Dr. Tahira Zafar Director HTC HPWS about the current state of Haemophilia care in the country and the challenges and obstacles faced by the patients and the care givers. The development of an adult HTC at PIMS with support from the ED and hospital management was appreciated. After this Mr. Brian was taken to MoH in Islamabad to meet Director MoH ,Razia Safdar - Director MoH. & Rai Nasser, Chief Economist of Planning Division of MoH. They discussed the development of an adult OPD facility at PIMS and Government procurement of CFC's. Members of BoG also met Mr. Brian O' Mahony to share their views with him.



# DEVELOPMENT GRANT PROJECT

The WFH Development Grant Program (DGP) aims to encourage new and innovative ideas and projects to support the Inherited Bleeding Disorders community worldwide. The goal is to register as many new patients of Hemophilia as possible through the planned activities. HPWS - Rawalpindi has made it a nationwide initiative by including all the other Chapters in it.



Awareness sessions in Educational & Religious Institutions



Awareness sessions in rural areas of Islamabad & Rawalpindi



Educational Seminars for Persons with Bleeding Disorders & their Caretakers



## SAVE ONE LIFE Beneficiary Story



'Taking the first steps in setting up your own business can be quite daunting', says Nusrat Shaheen, who was initially working in two houses to earn her livelihood. Her husband was a laborer on daily wages and together they were barely making ends meet. It was in 2019, when she realized that the only hope of survival was to take a leap of starting her own business to augment the family's meager income. The MEG grant was just what she needed! With the startup funds, I invested in 2 goats which cost me Rs. 30000 and sold them for Rs 35000. I was happy with the profit I made. My children too had access to pure goat's milk now. After this success, I again purchased 2 more goats and am planning to sell them soon. Nusrat makes regular trips to the nearby vet to ensure the goats remain healthy. Her son Usman helps her feed the goats and sometimes takes them in the nearby field for grazing. Seeing her plan translate into a successful venture is quite satisfying. She has plans to purchase baby goats and raise them till they are fully grown to sell before Eid.

**Nusrat Shaheen**





## SAVE ONE LIFE Beneficiary Story



I am Ahmad Raza, 21 years old person with Hemophilia A (moderate) registered in HPWS Rawalpindi. From very little age I have been continuously told by my parents and doctors about the importance of education, no doubt education is very important for every human but for a hemophiliac, education has extra importance as he/she cannot do any job that requires physical hard work, for example, labor work. Their whole future depends on good and high education so that they can get comfortable jobs. My parents never sacrificed on giving me the best education, they could not afford to send me to private school but for the sake of my future, they managed it. I passed my school with good grades and after that, I got admitted to college and passed it with good grades last year. Now it was time for me to get admitted in university but university fee was very high which was not possible for my father to manage, I submitted a scholarship application to SAVE ONE LIFE (SOL) for giving me a scholarship so that I can continue my studies, Dr. Munawar Sher Khan and HPWS Rawalpindi's staff helped me with this and with the grace of Allah Almighty it was accepted and I got the scholarship. I took admission to International Islamic University Islamabad for BS English Language and Literature program and now I am in 2nd semester.

**Ahmad Raza**

# Events Gallery







In order to reach out to Persons with Bleeding Disorders, HPWS Rwp hosts multiple events every year. This year we had a seminar on WFH and DGP activities, a magic show for children and a free movie screening, courtesy of Mrs. Samina Manzar, a Governing Board Member.





# Annual General Meeting

The Haemophilia Patients Welfare Society (Rawalpindi) had its Annual General Body Meeting at Pakistan Sweet Homes on the 28th of December 2019. Over 150 members & their families, staff, volunteers, consultants and paramedics staff attended making it a very successful meeting. The Haemophilia Patients Welfare Society has been providing the patients' treatment and care at self-help basis for number of years without any government support. Multiple sessions were held by our executive board and medical advisory board members. The passing of the Annual Report 2018 & the society's 2018/2019 audit (done by Faisal Latin & Co) was done by the President - Dr Munawar Sher Khan. The first segment was officially wrapped up with the serving of refreshments for the adults whilst the children participated in drawing/painting competitions. The second part of the meeting was patient oriented and had a in depth discussion and presentation by Prof Dr. Riaz Sheikh, Prof. Dr. Lubna Zafar on the topic of "Prevention and Treatment of Target Joints". Dr. Moazma Ahmed presented her thoughts on the benefits of physiotherapy for treatment of target joints. PwBD Tahir Javed shared his life story about the hurdles he's faced and how he's overcome them. This was followed by Save One Life's (SOL) sponsorship fund distribution for its beneficiaries. Mr. Ahmed Raza was presented with a scholarship to continue his studies without financial burden. Three very lucky women Nusrat Saheen, Salma Zaheer and Sameena Bibi were given enterprise grants. 2018-2019 was the year HPWS - Rwp focused on women empowerment and their input. These three grants awarded were proof of how many Pakistani women can achieve if given the right counseling and opportunities. The meeting was supported by Mr. Zamurrud Khan - Patron-In-Chief, Pakistan Sweet Homes & Ex-MD, Pakistan Bait-ul-Mal. HPWS Rwp extends its gratitude to all those who attended and especially Pakistan Sweet Homes for always hosting us when needed.



# DONORS

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- Brig. Retd. Rauf Malik
- Col @ Qamar Ul Islam
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- Dr. Khalid Masood
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- Dr. Nadeem
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- Dr. Nusrat Sharif
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- Ms. Nasra, Dr. Safia Akram, Mrs Tahira
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- Ms. Zahida Asif
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- OAKS Rawalpindi
- Sarhad Woolen Mills
- The Farogh-i-Islam Foundation

**Total Amount Donated: Rs. 54,48,181.00/-**

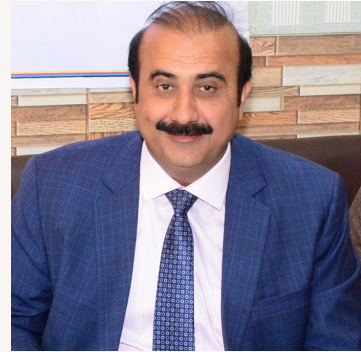
## Board of Governors



Maj. Gen Parvez Ahmed



Dr. Fazle Hadi



Mr. Zamurrud Khan



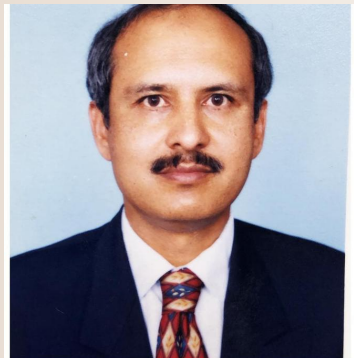
Prof. Asif Zafar Malik



Mr. Anjum Rafique Malik



Mrs. Samina Manzar



Dr. Mansoor Jan



Mrs. Fahmida Jan



Dr. Riaz Malik



Mrs. Shama Riaz Malik



## Medical Advisory Board



Prof. Tahira Zafar



Prof. Lubna Zafar



Dr. Nadeem Ikram



Prof. Riaz Ahmad



Dr. Khalid Aslam



Prof. Asif Zafar



Dr. Irum Naeem



Prof. Naeem Zia



Dr. Zahida Ahmed



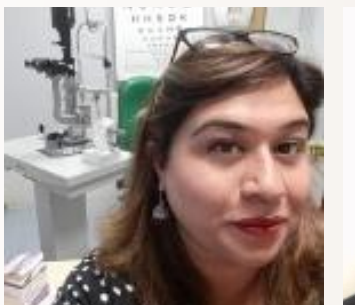
Dr. Ayesha Farid



Dr. Qasim Ali



Dr. Farkhanda Nazli



Dr. Sarah Zafar



Dr. Nauman Maqbool



Dr. Humaira Bilqis



# TEAM and MEMBERS





# AUDIT 2018-2019

**HAEMOPHILIA PATIENTS WELFARE SOCIETY  
RAWALPINDI (HPWS-RWP)  
ANNUAL ACCOUNTS  
FOR THE YEAR ENDED 30TH JUNE, 2019**

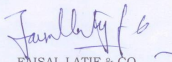
**Faisal Latif & Co.**  
Chartered Accountants

**AUDITORS' REPORT TO THE MEMBERS**

We have audited the annexed Balance Sheet of **HAEMOPHILIA PATEINTS WELFARE SOCIETY (PRIVATE) LIMITED** as at 30th June, 2019 and the related Income & Expenditure Account, Cash Flow Statement together with the Notes forming part thereof, for the year ended then ended (hereinafter referred to as the Financial Statement). These Financial Statements are responsibility of the management. Our responsibility is to express an opinion on these Financial Statements based on audit.

We have conducted our audit in accordance with the auditing standards as applicable in Pakistan. These standards require that we plan and perform the audit to obtain reasonable assurance about whether the above said statements are free of any material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the above said statements. An audit also includes assessing the accounting policies and significant estimates made by management, as well as, evaluating the overall presentation of the financial statements. We believe that our audit provides a reasonable basis for our opinion and after due verification, we report that:

In our opinion, the Financial Statements give a true and fair view of the financial position of **HAEMOPHILIA PATEINTS WELFARE SOCIETY (PRIVATE) LIMITED** as at June, 2019 and of the result of its operation and Cash Flows for the year then ended.

  
**FAISAL LATIF & CO**  
 CHARTERED ACCOUNTANTS  
 FAISAL LATIF FCA

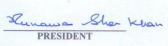
Islamabad:  
4th March 2019

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Ph: +92-51-22 80 226, Fax: +92-51-22 50 226 Email: faisal@moblink.blackberry.com

**HAEMOPHILIA PATIENTS WELFARE SOCIETY-RWP  
STATEMENT OF INCOME AND EXPENDITURE  
FOR THE YEAR ENDED 30TH JUNE, 2019**

	2019 Rupees	2018 Rupees
<b>INCOME</b>		
General donations	5,305,668	4,401,551
Grant from (SOL)	728,841	-
Grant from (WHF)	1,983,300	-
Patient fee	539,100	509,800
Factor sale	3,318,300	2,358,980
Membership fee	1,186,800	972,550
Other income	41,261	-
Physiotherapy	-	6,500
Gain/(loss) on investment	(5,315)	(32,906)
	<b>13,097,955</b>	<b>8,216,475</b>
<b>EXPENDITURES</b>		
Salaries, wages and benefits	1,710,083	1,634,800
Travelling and conveyance	125,436	26,371
Office supplies	174,192	48,291
Entertainment	-	65,306
Postage and delivery	5,249	14,535
Repair and maintenance	135,480	58,305
Bank charges	8,726	1,267
Rent, rates and taxes	900,000	600,000
Legal and professional charges	25,000	25,000
Utilities	135,155	137,483
Telephone & Internet	62,920	63,033
Subscription Books & Magazines	151,086	94,521
Depreciation	107,923	60,826
Miscellaneous	911,008	707,070
House hold expenses	62,531	-
Representation Expenses	412,252	116,250
Cost of factor	3,404,922	2,627,150
	<b>8,331,963</b>	<b>6,280,208</b>
<b>Surplus / (Deficit) for the year</b>	<b>4,765,992</b>	<b>1,936,267</b>

The annexed notes form an integral part of these financial statements

  
**PRESIDENT**



To our staff, you're our strength. Your service and commitment towards this organization is exceptional. Together, let us scale new heights and make impossible possible.

A dynamic Society taking haemophilia care to another level. HPWS Rwp provides free professional advice and medical assistance to haemophilia patients. The Chapter has strong links with the Haemophilia Foundation Pakistan, HPWS Chapters in the country and with the World Federation of Hemophilia (WFH) based in Montreal, Canada.

### Our Contact

+92 (051) 8432751/2

info@hpwsrwp.org.pk

1st Floor Thalassaemia House, Opposite RMC, Tipu Road, Rawalpindi

<https://hpwsrwp.org.pk>

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#### For Donations

Account Name: HPWS Rwp

Account No: 0504-003166320-3

IBAN: PK21 HABB 0005 0400 3166 3203

Bank Name: Habib Bank Ltd,

Satellite Town Branch Rwp