Haemophilia Patients Welfare Society Rawalpindi

Annual Report 2020







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ABOUT US

HAEMOPHILIA PATIENTS WELFARE SOCIETY RAWALPINDI

The Haemophilia Patients Welfare Society Rawalpindi is a dynamic voluntary, non-profit philanthropic organization established in 1999 by a group of medical professionals and patients.

Mission

To establish an integrated community-based service network aimed at improving the overall health status of Patients with Inherited Bleeding Disorders by providing them with quality care and support.

Objectives

- To provide information and guidance about the disease to patients, families, care givers, public and health authorities
- Increasing the number of diagnosed patients
- Lab facilities for accurate diagnosis.
- Development of treatment guidelines & protocols
- To provide timely and adequate treatment to patients
- To provide publications about the disease
- To raise funds for the medical treatment of these patients
- To support the women and children of these families for better education and improved income

HAEMOPHILIA TREATMENT CENTRE RAWALPINDI

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 in the twin cities of Rawalpindi & Islamabad.

Services

- Medical checkup, MO/Consultant
- Treatment (as per Policy)
- Referrals to & consultations by our Medical Advisory Board (MAB) & relevant Doctors at Haemophilia Friendly Hospitals (HFH)
- Admission in HFH's if required & provision of protocols & haemostatic cover per requirement
- 24 hour on call service for emergencies
- Emergency care per policy
- Physiotherapy sessions
- Counseling

Haemophilia Patients Welfare Society Rawalpindi

- Training to prepare factors & infuse factors
- Awareness activities, Seminars & workshops
- Lab diagnosis
- Development of medical literature, protocols & guidelines
- Continuing Medical Education & training of doctors, nurses & paramedics
- Research





MESSAGE FROM THE PRESIDENTS HPWS

OUTGOING PRESIDENT

Dr. Munawar Sher Khan

A tumultuous year indeed for the whole world and for us too.COVID 19 changed the world and we adapted quickly.

Having handed over my duties to Dr. Lubna Zafar, Vice President of our Chapter this will be my last message as President, hence I want to thank all those who reposed their trust in me six years ago and then re-elected the same Executive Board (EB) for a second tenure. The transformative changes and achievements brought about during this time could not have been possible without the commitment of the EB and our absolutely amazing staff whose devotion to the Society is highly commendable. I would also like to express my gratitude to the World Federation of Hemophilia for their continuous support for sustainable development along with the Humanitarian Aid Agreement, Save One Life for supporting and educating needv individuals, Pakistan Centre for Philanthropy for their work in developing a documentary highlighting our work, Dr. Tahira Zafar for editing the "Haemophilia Handbook" and to all those who contributed to its development, those philanthropists' whose donations have helped the Society save lives and prevent disabilities and last but definitely not the least our treasured volunteers.

"There's only one thing more precious than our time and that's who we spend it on" Leo Christopher



PRESIDENT

Prof Dr. Lubna Zafar

Assalam O Alaikum

I feel honored to step in as the President of this wonderful organization. I have been associated with the HPWS Rwp. right from its inception. However, as President it will be a challenging undertaking to fulfil the obligations and expectations associated with this appointment. I am confident that with the wonderful team work in vogue at HPWS Rwp, it will be achievable.

We are facing a lot of challenges. We endeavor to complete all tasks in hand and those coming up in the New Year. COVID-19 pandemic has renewed our resolve and taught us to keep changing and evolving and becoming self-sustaining and stronger than before. Like they say "when the going is tough, the tough get going".

I am sure that with the support of our hemophilia and bleeding disorders community as well as our National and International collaborators we will meet all challenges successfully.

Looking forward to a brilliant 2021.

MESSAGE FROM DIRECTOR HAEMOPHILIA TREATMENT CENTRE



Prof. Dr. Tahira Zafar

My message goes out at a time of extreme crisis the world over due to COVID pandemic. It has no doubt tested our resilience as well. I am however pleased to report that the collective strength & resolve of our staff in the face of this global adversity has led to continuation of all services, routine, emergency & lifesaving, throughout this pandemic.

The COVID guidelines, developed by our HTC were the first ones in the country. The best thing however was their excellent implementation by our staff and adherence to them by our patients. Together we have proven that we can work in the most demanding of circumstances!

We have also continued active participation in all virtual International Inherited Bleeding Disorders events and our staff has benefitted from webinars and educational activities.

We have gathered strength & inspiration from the marvelous work we have been able to do & look forward to a very productive new year

OUR STAFF

Consultants (Volunteers)









Prof. Tahira Zafar

Porf. Lubna Zafar

Dr. Nadeem Ikram

Dr. Rana Zeeshan

The Staff



Dr. Bilquis Sohail Medical Officer Incharge



Naveed Inderyas Manager Finance & Admin



Alamgir Abbasi HTC Coordinator



Miss Ayesha Nursing Assistant



Fayyaz Ahmad Office Supervisor



Noreen Bibi Receptionist

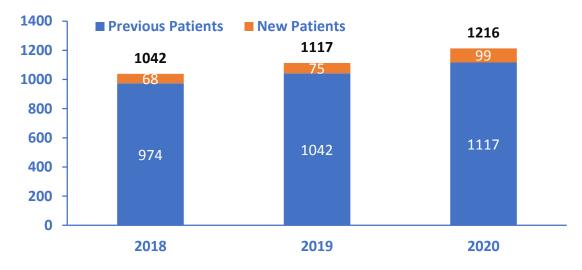


Ammar Saleem Data Operator

HTC DATA 1ST JAN - 31ST DEC 2020

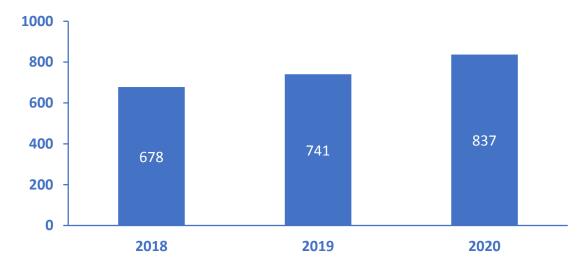
HTC Patients

Total registered patients in 2018: 1042 (68 new registrations) Total registered patients in 2019: 1117 (75 new registrations) Total registered patients in 2020: 1216 (99 new registrations)

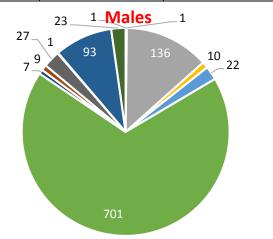


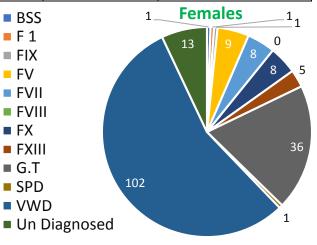
Nationally registered patient details

Nationally registered patients in 2018: 678 Nationally registered patients in 2019: 741 Nationally registered patients in 2020: 837

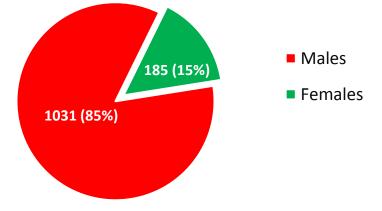


	Total Pat	ients	1216		
Males 1031			Females 185		
Sr. #	Diagnosis	Number of Patients	Diagnosis	Number of Patients	
1	BSS	1	BSS	1	
2	F 1	1	F1	1	
3	FIX	136	FIX	1	
4	FV	10	FV	9	
5	FVII	22	FVII	8	
6	FVIII	701	FVIII	0	
7	FX	7	FX	8	
8	FXIII	9	FXIII	5	
9	G.T	27	G.T	36	
10	SPD	1	SPD	1	
11	VWD	93	VWD	102	
12	Un Diagnosed	23	Un Diagnosed	13	
	Total	1031	Total	185	



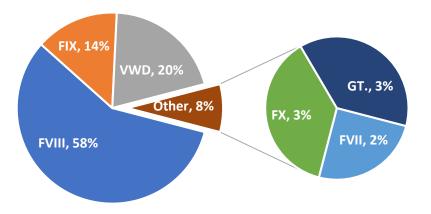






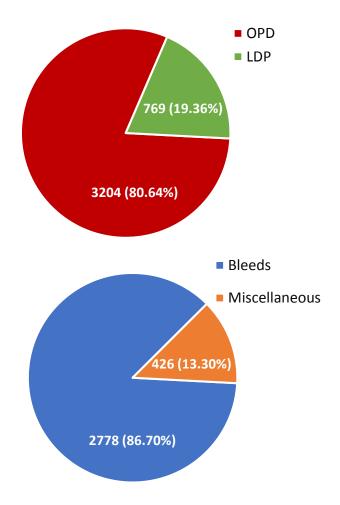
New registrations 99

FVIII		57
FIX		14
VWD		20
	FVII	2
Others	FX	3
	GT.	3



Patient Visits

		Knee	819	
		Ankle	277	
	Joints	Elbow	383	1725
		LIDOW	505	
		Нір	246	
	Nose			76
Bleeds	Menorrhagia			30
	Dental			198
	GIT			46
	Soft Tissue/ Muscle			514
	ІСВ			15
	Others			174
Misc.			426	



Admissions 50

Bleeds						Operations	
Joints		GIT	ICB	Others C		Ovarian Cyst	1
Knee	10	7	7	Urinary	1	Orchidectomy	1
Нір	6			Dental	2	Appendectomy	2
Elbow	1			Nose	2	Fracture Femur	3
Shoulder	1			РРН	1	Polypectomy	1
				Calf	1	Craniotomy	1
				Forehead	1	Plural effusion	1
Total	18	7	7		8		10

Referrals 237

Dental	Physiotherapy	Orthopedics	Investigations
1	26	18	192

Factor Consumption

Factors	Units	Patients	Average IU per patient
FVIII (OPD)	23,35,940	391	5974
FVIII (LDP)	303,500	14	21678
FIX	385,250	62	6213
VWF	363,600	87	4179
FVII	209 mg	23	9 mg
FEIBA	23,000	04	5750

SUCCESS STORIES

Young Female with FV Deficiency

Admitted with severe abdominal pain and bleeding in stools Diagnosed as having Inflammatory bowel disease Treated & Discharged after 15 days

Male 13 years FIX Deficiency

History of fall from roof resulting in fractures & Intracranial bleed Treated with FIX concentrates according to HTC protocol Discharged after 5 days

Female vWD

Admitted with severe lower abdominal pain. Investigations: Abdo U/S Rt. Ovarian Cyst rupture. Treatment: Exploratory Laparotomy and Marsupialization of bilateral Ovarian Cysts under vWF cover Discharged after 22 days

Male FVIII Deficiency

History of fall with Headache & vomiting. **Investigations: Intracranial Bleed** Treatment: Long acting FVIII concentrates according to HTC Protocol. Craniotomy was done successfully. Discharged after complete recovery.

Male F IX Deficiency

History of fall from height resulting in fracture of femur. Treatment : Intramedullary elastic nailing long acting FIX coverage was provided per HTC protocol Discharged after 11 days of hospitalization.









THE HTC PROJECTS

- HCV Project in collaboration with Benazir Bhutto Hospital (BBH) Rawalpindi
 - o Patients on treatment 21
 - o Treatment: Sofiget 400 mg, Mydecla 60 mg for 3 months
- Low Dose Prophylaxis (LDP) in Haemophilia A
 - Factor donation from WFH, Humanitarian Aid Project
 - Started on 17th April 2018 Patients 14

Dose of Factor VIII at 20 IU	J/kg IV weekly (Advate	250 IU & Koate 250 IU)

Patients		Fraguanay	Bleeds	
Patients	Dose IO	Dose IU Frequency		Traumatic
07	250	Weekly	Nil	Yes
06	250	Twice Weekly	Nil	Yes
01	750	Weekly	Yes	Synoviorthesis





LDP joint assessment by Dr. Moazzama at Physiotherapy Dept. BBH



LDP Consultation & Infusion at HTC by our MO & Haemophilia nurse

• Training of patients & parents to prepare & infuse factors

Majority of patients (grownups and adults) and parents are trained to prepare and infuse factors. It facilitates home infusions / emergency cover for factors.

Training is provided by HTC Nursing staff. Factor Preparation 92% Factor Infusion 50% Factor Infusion Training 95%



Hifazat e Najam Treatment Support Project

Hifazat e Najam Project helps those Persons with Inherited Bleeding Disorders (PWBD), registered with the HPWS Rwp who cannot afford to pay for factors

Beneficiaries 29



• Hifazat e Jan Saving lives Project

Helps in treating patients with life threating bleeding with no donated factors & patients unable to purchase factors themselves

• WBDR Project

Development of software for Standardized data collection and analysis with International Collaboration



HTC staff with OliveCliq team, working on software development

ACTIVITY REPORTS

Dr Saad Jamshed from Mary M Gooley Hemophillia Center Rochester, USA visits HTC Rawalpindi

Dr. Saad Jamshed MD, Associate Head of Haematology / Medical Oncology from Rochester Regional Health, USA visited the HTC HPWS Rwp on 20 Feb 2020 with a view to developing close liaison between the 2 center was discussed. The emphasis on joint health, physiotherapy and Synoviorthesis were highlighted. He offered help and guidance in all clinical & organizational data as well as help with research & publications.



Dr. Tahira Zafar represented Pakistan at this global summit discussing the challenges Pakistani Women & girls with inherited bleeding disorders face



World Federation of Hemophilia (WFH) Virtual Summit, 14th to 19th June 2020, a great event to bring the global bleeding disorder community together

The Haemophilia Care Physicians (HCP's) at Haemophilia Treatment Centre (HTC) of HPWS Rawalpindi, participate actively in the World Federation of Hemophilia (WFH) virtual Summit











Prof. Tahira Zafar **Director HTC D**

Porf. Lubna Zafar **Director HTC**

Dr Bilguis Sohail MO Incharge HTC Dr. Rana Zeeshan Dr. Nadeem Ikram **Consultant HTC**

Consultant HTC

HPWS Rwp rises to COVID 19 challenge, continuing to work, beating the pandemic The HTC has remained open due to the commitment of the staff to continue to work & provide lifesaving services to the haemophilia community



The most important challenge, right from the start of the COVID pandemic, was to keep the HTC open for treatment and safety of patients & staff . This delicate balance was achieved by the dedication of our staff to implement the preventive measures and by cooperation of our patients to adhere to it



Examination, at a distance working with social distancing

HTC Rwp representation at WFH Forum, Master trainers for the regional training webinar



AWARDS

WBDR Research Support Program Award for software development for uniform & standardised patient data entry

WBDR Data excellence award



PUBLICATIONS

- Brochures for Haemophilia Patients
- HTC Management booklet
- COVID 19 guidelines for HTC's
- Haemophilia Handbook for care givers



HPWS & HTC STAFF MEETINGS

12

- HPWS Meetings
- HTC Meetings 24



HPWS, Rwp & HTC Staff Meetings



12 Executive Board Meetings Online and Personal in Covid-19 Situation

HPWS RAWALPINDI ACTIVITIES

Collaboration with Mary M Gooly Hemophlia Centre, Rochester, USA

Dr Saad Jamshed MD Associate Head of Hematology/Medical Oncology from Rochester Regional Health, USA Visited the HTC HPWS Rwp on 20th Feb, 2020



Capacity Building of Youth and Women Group, HPWS, Rwp Youth and Women Meeting on 29th Feb, 2020



Development Grant Project

Awareness session at Karachi Chapter on 02nd Mar, 2020



REACHING OUT

Registration of New Patients at HPWS, Rwp from Faisalabad (Hilal-e-Ahmar) on 13th Mar, 2020



World Hemophilia Day & Save One Life Fund Distribution on 17th April, 2020 in Covid-19 days



Save One Life Funds Distribution in Covid-19 situation,

World Haemophilia Day Celebration 17th April, 2020 at HPWS, Rwp



April 17, is World Haemophila Day (WHD), a very important day for HPWS, Rwp and the whole Bleeding Disorders Community. In spite of COVID pandemic the WHD was celebrated, though virtual



Celebration of Pakistan Independence Day at Society 14th Aug, 202



A Dengue Awareness Program at HPWS in collaboration with Social Welfare Department



Mr. Raja Imran from Social Welfare Department and HPWS, Rwp Staff



Save One Life Funds Distribution on 17th Dec

Successful Venture in collaboration with Save One Life (MEG)



Samina Bibi opened up a grocery store with SQL support in April 2020. Times had been

Samina Bibi opened up a grocery store with SOL support in April 2020. Times had been pretty tough with the pandemic-imposed lockdown.

To make matters worse, her husband who was a tractor driver had also been jobless for more than five months. Determined to fight poverty, she felt she needed to do something to supplement her income and decided that it was the right time to start a business. 'Running a business proved a little difficult at first because I had no knowledge of the financial aspect', she recalls. There was also a big general store in her neighborhood and she wasn't sure about the response her humble effort would get. However, her hard work and dedication paid off and there was a consistent line of customers at her shop!

Samina says 'It has not been easy getting a business going but I guess I was lucky to have assistance at the right time'

She goes on to say 'Setting up my own business has boosted my self-esteem. To have gotten this far in these tough times is something I'm very proud of!'

Farewell to Dr. Munawar Sher Khan



Member of young Lawyers forum, High Court Islamabad visited HPWS RWP.



Group of Lawyers (Adv. Usman Butt, Khawar Nawaz, Nafees Khan and Ali Waqas offered their Free services as & when required by HPWS, Rwp

Launch of Hemlibra, an innovative treatment for Haemophilia with donation from HAP of WFH



Staff taking COVID-19 Challenge head on!



VISITORS' GALLERY

Mr. Masood Farid (President HFP)



Dia Welfare Organization Sialkot Team



Mr. Ali (Evaluation Team PCP)



General Parvez Ahmad (Member BOG)



Zamarud Khan (Member BOG HPWS RWP & MD Pak Sweet Home)



Mr. Anjum Rafiq (Member BOG)



Mr. Ahmad Nadeem, HPWS Rwp Documentary



ROUTINE ACTIVITIES AT HPWS, RWP



Maj. GEN. Pervaiz Ahmad



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Dr. Riaz Malik



Prof. Dr Asif Zafar Malik



Mrs. Fahmeda Jan



Mrs. Shama Riaz Malik



Mrs. Samina Manzar



Mr. Zamurrud Khan



Mr. Anjum Rafique Malik



Dr Fazale Hadi

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Ms Rabia Saleem



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Mr Hassan Raza



Mr Ali Raza Marchal



Ms Abira Maheen



Ms Fouzia Parveen



Mr Shahzaib Malik



Mr Uzair Hussain

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Dr Ayesha Fareed



Dr. Nauman



Prof. Naeem Zia



Dr. Humaira Bilquis



Dr Sarah Zafar



Dr Zahida Ahmed

THANK YOU FOR YOUR DONATIONS, YEAR 2020

- Alpha Evolution Enterprises
- Brig Naeem Akhtar khan
- Col Syed Qamar-ul-Islam
- Dr. Anwar Gul
- Dr. Ayesha Junaid
- Dr. Hanif Malik
- Dr. Imran
- Dr. Lubna Zafar
- Dr. Mammon
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- Mr. Tahir Javid
- Ms. Uzma Azam
- WBDR

LIST OF ABBREVIATIONS

Abdo US	Abdominal Ultra Sound	IU	International Units
BOG	Board of Governors	IV	Intravenous
BSS	Bernard Soulier Syndrome	LDP	Low Dose Prophylaxis
EB	Executive Board	MAB	Medical Advisory Board
FI	Coagulation Factor I	MD	Managing Director
FIX	Coagulation Factor 9	MEG	Mini Enterprises Grant
FV	Coagulation Factor 5	МО	Medical Officer
FVII	Coagulation Factor 7	OPD	Out Patients Department
FVIII	Coagulation Factor 8	РСР	Pakistan Center for Philanthropy
FX	Coagulation Factor 10	PWBD	Persons With Bleeding Disorders
GIT	Gastrointestinal Tract	SOL	Save One Life
НСР	Haemophilia Care Physician	SPD	Storage Pool Disorder
HCV	Hepatitis C Virus	vWD	von Willebrand Disease
HFH	Haemophilia Friendly Hospitals	vWF	von Williebrand Factor
HFP	Haemophilia Foundation of Pakistan	WBDR	World Bleeding Disorders Registry
нтс	Haemophilia Treatment Centre	WFH	World Federation of Haemophilia
ICB	Intracranial Bleed	WHD	World Haemophilia Day

HPWS, RWP AUDIT REPORT 2019-2020



6 h. O. Dan, 2020



OUR COMMITTED AND DEDICATED STAFF MEMBERS

HPWS Rawalpindi, a dynamic Society, taking Haemophilia care to another level HPWS Rwp provides professional advice and Medical Assistance to the Haemophilia community. It collaborates closely with Haemophila Foundation of Pakistan and World Foundation of Haemophilia

Our Contact

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७: <u>https://hpwsrwp.org.pk</u>
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