

HWSK ANNUAL REPORT 2020



**Do not let your bleeding disorder keep you behind.
Stand up and fight against it....**

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ABOUT HWSK

Hemophilia Welfare Society Karachi has been working since 2016. It was established by a group of patients who had hemophilia themselves or their parents. The purpose of such a combination of persons in the mix was the realization of the intensity of pain and sufferings of the patients. We are providing treatment, rehabilitation, and education to the bleeding disorder community in Sindh.

We Are Registered With:

- The Social Welfare Department of Sindh (SWDS),
- Sindh Healthcare Commission (SHC)
- World Bleeding Disorder Registry (WBDR)

We Are Affiliated With:

- The World Federation of Hemophilia (WFH)
- Husaini Hematology and Oncology Trust (HHOT)
- National Institute of Blood Diseases (NIBD)
- The Indus Hospital (TIH)

MESSAGE OF PRESIDENT

- As a hemophiliac myself, I thought of myself as a bane and burden on the earth with no ease in sight. But now standing on the 42nd rung of the ladder of my life, I think it was a boon because though hamstrung in many ways it was a Godsend opportunity for me to cling to and work for the fellow hemophiliacs and bring about a qualitative change in their lives.
- It reinvigorated my resolve and I gleefully accepted my tryst with destiny.
- I want the same spirit to permeate in other hemophiliacs so that when I pass the baton to my juniors, they take the cause to newer levels and this journey continues from one state of betterment to another.



HEMOPHILIA & COVID - 19

- Covid-19 has taken its toll on the whole world and we in Pakistan also got affected by it and the menace is still running havoc.
- We, as hemophilia treatment organization, were active in those difficult times by adopting compliance with the SOPs, and by the grace of God not a single first responder was affected by it.
- In recognition of our efforts, Novo Nordisk Hemophilia Foundation (NNHF) distributed PPEs to us through the Hemophilia Foundation of Pakistan (HFP).
- The epidemic of the corona is having a detrimental effect on human health as well as economic life, adding to the hardships of hemophilia patients. The HWSK took steps in this regard and distributed rations to deserving patients.



PATIENT REGISTRY

Last year in 2019 registered patients were:	658
New Enrolled Patients:	84
Total registered patients	742

Distribution of Registered Patients According to Bleeding Disorder	
TYPES OF DISORDERED	NO. OF PATIENTS
Hemophilia A [VIII]	538
Hemophilia B [IX]	116
Von Will brand	51
Factor XIII deficiency	10
Factor I deficiency	8
Factor X deficiency	5
Factor V+VIII deficiency	4
Factor VII deficiency	3
Factor V deficiency	1
Factor II deficiency	1
Fibrinogen	1
Platelet Dis Bernard	1

UTILIZATION OF CLOTTING FACTOR CONCENTRATE

We are getting Clotting Factor Concentrates for On-Demand Treatment from World Federation of Hemophilia's Humanitarian Aid Program through the ages of Hemophilia Foundation Pakistan and are providing free of cost treatment to our registered patients. In Sindh province we saved many lives and have done successful surgeries, treatment of patients suffering injuries in road accidents. In this year we infused **2,293,250 IUs** of Clotting Factor Concentrates (CFCs) Factor VIII and Factor IX both, while the treatments of bleeding episodes were **4,144**.



Clotting Factor Concentrates Utilization Report - 2020

S.NO	DONATE BY	PRODUCT	TREATMENT TYPE	TOTAL IUs	Treated Bleeding Episodes
1	World Federation of Hemophilia	Anti-Hemophilia Factor VIII Inj.	On Demand	1,987,568 IUs	3631
2	World Federation of Hemophilia	Anti-Hemophilia Factor IX Inj.	On Demand	239,750 IUs	438
3	World Federation of Hemophilia	Bypassing Agents	On Demand	26,500 IUs	24
4	National Institute of Blood Disease	Anti-Hemophilia Factor IX Inj.	On Demand	17,500 IUs	43
5	World Federation of Hemophilia	Anti-Hemophilia Factor VIII Inj.	Surgery	111,800 IUs	8
TOTAL				2,293,250 IUs	4144

WFH LOW DOSE PROPHYLAXIS PROGRAM

Low-dose prophylactic therapy reduces the total number of bleeds and improves the quality of life and the ability to perform increased daily activities for the children with severe hemophilia A. We are getting Anti Hemophilia Injection from the World Federation of Hemophilia prophylaxis Program through the ages of Hemophilia Foundation Pakistan in which we enrolled **15** Registered Hemo-kids of the age from **1-12 years** in Sindh province who are getting twice a week CFC doses free of cost.



Low Dose Prophylaxis Utilization Report – 2020

“AN ORGANIZATION CONSISTING OF PATIENTS & PARENTS ASSOCIATED WITH HEMOPHILIA & OTHER BLEEDING DISORDER DISEASES”

Low Dose Prophylaxis Utilization Report – 2020					
S.NO	DONATE BY	PRODUCT	TREATMENT TYPE	TOTAL IU _s	Treated Bleeding Episodes
1	World Federation of Hemophilia	Anti-Hemophilia Factor VIII Inj.	Prophylaxis	1,150,00 IU _s	105

UTILIZATION OF BLOOD BY-PRODUCTS –FFPs & CPs

Blood by-products Fresh Frozen Plasma (FFP) and Cryoprecipitate are an alternative treatment of Hemophilia & for other bleeding disorders. In this regard, we are getting these products as humanitarian Aid from Husaini Hematology and Oncology Trust (HHOT), National Institute of Blood Diseases (NIBD), The Indus Hospital (TIH). In this year alone we utilized **12,028 units** to treat 3,628 **Bleeding** Episodes of our registered patients.



FFPs / CPs Utilization Report – 2020

FFPs / CPs Utilization Report – 2020				
S.NO	DONATE BY	PRODUCT NAME	UNIT / BAG	Treated Bleeding Episodes
1	HUSAINI BLOOD BANK	FFP/CP	3728	1399
2	NIBD BLOOD BANK	FFP/CP	4678	1403
3	INDUS HOSPITAL	CP/CS	3622	826
	TOTAL		12028	3628

APPRECIATION & ACKNOWLEDGMENT BY WFH

The WFH Humanitarian Aid Program made it possible for a man to survive a serious accident in Hyderabad, Pakistan. Sarfaraz 22-year-old man with hemophilia A was involved in a car accident on the highway and was badly wounded. Thanks to [WFH Humanitarian Aid Program](#) donations, he was able to get the factors he needed badly to make a full recovery.



Sarfaraz's accident happened on April 23, 2020. He was immediately brought to the Civil Hospital in Hyderabad and then was shifted to the National Institute of Blood Disease & Bone Marrow Transplantation (NIBD) hospital, 150 kilometers away from Hyderabad, Pakistan. There, he was placed under the care of Munira Borhany, (MD). Thanks to the efforts of the Hemophilia Welfare Society Karachi (HWSK) and the Hemophilia Foundation of Pakistan (HFP), he received a critically needed donated products provided by the WFH Humanitarian Aid Program.

The donated factors saved Sarfaraz's life. He suffered massive bleeds covering his whole head, face, and eyes. He also had multiple bruises and lacerations on his body. Fortunately, CT scans showed neither intracranial bleeding nor any fractures. From his time in the emergency room till his discharge, he received donated factors several times. He continued receiving factors after his discharge and is currently under the care of the HWSK Hemophilia Treatment Centre ([HTC](#)) where he got himself registered.



Thanks to the WFH Humanitarian Aid Program, Pakistan has received over 38 million IUs of Clotting Factor Concentrates (CFCs) since 2015, with over 8 million IUs of CFCs sent in 2019 alone. These donations have allowed hundreds of people—including children—to enjoy a better quality of life.

WORLD HEMOPHILIA DAY - 2020

Adapting to Change, Sustaining Care in a New World

World Hemophilia Day is about bringing the global bleeding disorder communities together. With the COVID-19 pandemic having a major impact on people with a bleeding disorder, that objective has never been more important. The world has changed greatly over the last year, but one thing has not: we are still in this together. Join us on April 17, 2021 and tell us how you have adapted to change during this unique period time, and how you are working hard to help sustain care in a new world!



Due to the prevalence of Covid-19, we could not celebrate hemophilia day in a befitting way, this year, in which the patients and their parents, doctors, and other stakeholders are usually invited and is celebrated in a kind of a carnival with festive activities: but this time we did activities in the print, electronic and social media instead, in which patients and their parents' perspective was highlighted, full interviews were aired, short clips of those interviews were posted on social media, with the aim of generating awareness of hemophilia and its concomitant complexities in the hemophiliacs.

EDUCATION SUPPORT PROGRAM SAVE ONE LIFE (SOL) FUNDS DISTRIBUTION

Save One Life (SOL) funds distribution done to deserving bleeding disorder patients for their school expenses during the last six months. It is more than one and a half-decade now that we have been distributing these funds to the poor students to enable them to continue their education. We shortlisted some 25 such patients. The fund comes through Save One Life Inc., an organization headed by [Laurie Kelley](#), who is a mother of a hemophiliac herself.



We are thankful to Mr. Asad Ali-CEO Husaini Hematology & Oncology Trust (HHOT), Dr. Sarfraz H. Jafri for lending us their support by giving us their auditorium to do the program.

We thank Laurie and her SOL team for their willingness to earmark some amount for patients in Sindh province. We are especially thankful to Dr. [Munawar Sher Khan](#) for coming here to attend this program from Rawalpindi Chapter.



HEMOPHILIA RESEARCH WITH KIBGE

Hemophilia Advocacy: Meeting with Dr. Sitwat Zehra Associate professor of Dr. Abdul Qadeer Khan Institute of Biotechnology & Genetic Engineering (KIBGE).

We have entered a contract with Dr. Abdul Qadeer Khan Institute of Biotechnology & Genetic Engineering (KIBGE) University of Karachi. HWSK has the resilience to address the hemophilia issues at different levels, both immediate and long term. It is working hand in hand with those organizations which are doing research on hemophilia by providing data available with us.

KIBGE is one of the most prestigious research institutes in the country. It has active collaborations with several research / academic institutes of the world.

KIBGE is initiating a research project based on the “Polymorphism in Immune Regulatory Gene and Association with Inhibitor Production in Hemophilia A”. For this purpose, 100 blood samples were required from Hemophilia A patients and 100 age and sex-matched controls. To facilitate this research, the HWSK is collaborating with KIBGE.



HEMOPHILIA ADVOCACY & COLLABORATION WITH INDUS HOSPITAL

Another Step Forward in improving the Quality of Life of Hemophiliacs through Hemophilia Advocacy. The parents of hemophiliacs always had to bear the cost of hospitalization for surgeries, diagnostics, etc. We are struggling to put this pressure off the shoulders of patients and their parents.



With this objective in mind, we had a very positive meeting with Dr. Saba Jamal, in charge of The Indus Hospital Blood Center. The organization planned to use all the resources available to provide better treatment to every patient in Sindh province including rural areas. It was also decided in the meeting to enhance the existing scope of service being given to hemophiliacs in terms of diagnostics, hospitalization, pre, and post-operation care.

“The Indus Hospital is a tertiary care multidisciplinary hospital and healthcare provider in Pakistan. It also has under it three Regional Blood Banks. Its mission is to create an excellence-driven, comprehensive, compassionate, free of charge, replicable healthcare system accessible to all”.

It is already supplying us cryo precipitates in bulk quantities which has increased our leverage in treatment management and filled the gap to a great extent between demand and supply for the patients. This also helps us, besides catering to the needs of the hemophilia A and B patients, to bolster our capacity to give treatment to the rare bleeding disorder patients who only need plasma or CP. The other important source is the Coagulating Factor Concentrates (CFCs), which we get from the World Federation of Hemophilia through the aegis [Hemophilia Foundation – Pakistan](#) (HFP).



THE FIRST PROPOSAL FOR CFC PROCUREMENT SUBMITTED TO PROVINCIAL HEALTH MINISTER, SINDH

Another successful step forward in the Hemophilia advocacy drive!

A historical achievement indeed by HWSK in collaboration with the Govt. of Sindh in that we presented to the Sindh Government a first of a kind proposal developed by a dedicated team of Hemophilia Welfare Society Karachi including Dr. [Munira Borhany](#), which was given the task of developing such a document, which, if implemented in its entirety, would bring about a qualitative change in the treatment of hemophiliacs of Sindh Province.



Here we would like to mention the initiative taken by Dr. Durr-e-Naz, Director, Sindh Blood Transfusion Authority. Had it not been for the untiring efforts on the part of Dr. Durr-e-Naz and her team, it wouldn't have been possible to have such a productive meeting with Dr. [Azra Fazal Peechoho](#), provincial Health Minister of Sindh Govt.



We would also like to thank [Rana Saifi](#), Regional Manager, Middle-East, and Asad Haffar, Director, (WFH) who gave their invaluable input in developing this document. We hope that a lot of good would come out following this meeting and a more robust collaboration would evolve between Hemophilia Welfare Society Karachi and govt. of Sindh.

Furthermore, we hope that with the help of Regional Blood Centers in Sindh, the govt. will be able to set up a plasma fractionation facility with the help of pharmaceutical companies to make in-house coagulation factor concentrates (CFCs) from screened plasma. This would go a long way in enhancing the quality of treatment for hemophiliacs. We hope that this would become a role model for the Hemophilia Foundation - Pakistan chapters (hemophilia societies) working in other provinces to take a cue from us and work in collaboration with their respective provinces.



HEMOPHILIA ADVOCACY AT THE SOCIAL WELFARE DEPARTMENT

The Department of Social Welfare organized a coordination session with other NGOs to find out the common ground where all the NGO could make synergetic efforts for the common good and to from a common platform for the general good of the NGOs.



We availed of the opportunity to highlight the problems faced by the hemophilia community, and how best it could best solved if we join hand with other organizations and using their strengths to our advantage.

VOICE OF HEMOPHILIA KIDS

18-month-old suffers from Hemophilia and TOF Family, Welfare Society seeks support to treat the rarest case. Karachi, Oct 13: The first case of a child suffering from hemophilia and heart disease has come to the fore. The 18-month-old child is suffering from double pain. Hemophiliac Muhammad Ahmed suffers from the complex congenital heart disease TOF, Tetralogy of Fallot, as well. The parents have appealed to philanthropists for help in providing treatment to their only son.



According to details, Saman Afif, a resident of Gulistan-e-Jauhar, along with her 18-month-old child and husband Afif Ahmed, reached the treatment center of Haemophilia Welfare Society in Karachi for treatment of her child.



Addressing a press conference at the center on Tuesday, along with President Haemophilia Welfare Society Karachi Raheel Ahmed and hematologist Dr. Munira Burhani, she said that her son Mohammad Ahmed was suffering from congenital heart disease TOF, Tetralogy of Fallot. Within a few months of birth, we learned that he had hemophilia also, a bleeding disorder.

Mohammad Ahmed has four heart defects. Doctors will operate on him in three stages. The mother said that the child's health suddenly deteriorates; he stops breathing and faints. Saman Afif appealed to philanthropists to help save her only son Muhammad Ahmed. The mother said that the family had spent whatever money they had. Moreover, the Founder President of, Hemophilia Welfare Society Karachi, Raheel Ahmed talking to the media said that Muhammad Ahmed will have three operations in the span of four years. He said that complete treatment of Mohammad Ahmed will cost around Rs12.5 million, adding that only injections of Factor-9 will cost more than Rs 10.04 million.



Raheel Ahmed said that the Hemophilia Welfare Society would provide anti-hemophilia Factor 9 injections donated by WFH worth Rs 2 million from its own funds. He further said that it is impossible to manage the amount required for the treatment without the help of philanthropists.

Dr. Munira Borhany, a hematologist, said that the affected child needs a hospital where all the departments are available for treatment, during the operation and it will be a big challenge to stop the bleeding after surgery.

The press conference was also attended by the child's father Afif Ahmed, General Secretary Hemophilia Welfare Society Shahid Dawood, and Fakhr-e- Alam Zaidi.

INAUGURAL CEREMONY OF OUR NEW MODEL HEMOPHILIA CENTER

A Quantum Leap Forward

Hemophilia Welfare Society Karachi held an inaugural ceremony at its new premises. It was an honor for us that Dr. Abdul Bari Khan-CEO, [The Indus Hospital](#)

(TIH) accepted our request to be the chief guest and cut the inaugural ribbon. Accompanied with him was Dr. Saba Jamal-Director Blood Center (TIH) who is a very important link between the HWSK and TIH.

We warmly welcomed Dr. Dur-e-Naz-Secretary, Sindh Blood Transfusion Authority, who accepted our invitation to come at the opening ceremony and has given assurance to have a close nexus between Sindh Ministry of Health and [Hemophilia Welfare Society Karachi](#) - HWSK

We also had the honor of being present on the occasion, our chief patron Mr. Anis ur Rehman who has been the driving force in taking the quality of hemophilia treatment a few notches up.

Also present was Dr. [Munira Borhany](#)-Consultant Hematology from [National Institute Of Blood Diseases & Bone Marrow Transplantation](#)- NIBD and who is also our Head of the Department (HoD) of the HTC and Dr. [Shabneez Hussain](#)-MD Fatimid Foundation, Mr. Asad Ali-CEO [Husaini Hematology & Oncology Trust](#). (HHOT), Doctor Sarfraz Jafri, HWSK Chairman-Medical Advisory Board (MAB), Mr. Ateeq-ur- Rehman,-MD [Afzaal Memorial Thalassemia Foundation - Official](#) (AMT)

In our new premises, we have a fully-fledged physiotherapy unit, which is very important for the hemophiliacs to render their joints safe from irreversible deformities and from recurring bleeds. We have also increased our capacity to store CFCs, blood components for other bleeding



disorder patients. We are now in a position to treat more patients at a time as we have an increased number of beds and have our own pharmacy from where the patients could get medicine free of charge. Not only that we have shifted to a new location which is spacious but we have also augmented our repertoire of treatment facilities to our patients in addition to the Coagulation Factor Concentrates (CFCs) that we get from the [World Federation of Hemophilia / Federación Mundial de Hemophilia](#)



(WFH) through the aegis of [Hemophilia Foundation – Pakistan](#) HFP, which are very dynamic organizations working for the cause of hemophilia.

And finally, we would like to extend our heartiest CONGRATULATIONS to the HWSK team and its volunteers. It would not have been possible to make the event a resounding success had it not been for their tireless efforts in this regard.

STRATEGIC PLAN FOR 2021

- HWSK aims to build Strong advocacy with the government as well as with the private sector.
- To establish Hemophilia Treatment Center–HTC in Hyderabad division and other remote areas, through outreach to provide treatment facilities at their doorstep.
- To maintain and improve quality of life by establishing a comprehensive physiotherapy unit.
- To disseminate awareness through Continual Medical Education–CME by conducting seminars and workshops in the medical and educational institution.
- To establish a pharmacy to provide medicine as well, besides the Anti-Hemophilia Injection and Blood by-products.
- To enhance Hemophilia Advocacy on Electronic and Print Media.
- To start registration of Hemophilia Carrier women.

OUR TEAM

Executive Body

Raheel Ahmed	President
Asghar Ali	Vice-President
Shahid Dawood	General Secretary
Shazia Malik	Joint-Secretary
Fakhr-e- Alam Zaidi	Treasurer

Medical Advisory Board-MAB

Dr. Sarfaraz Hasan Jafri	Chairman MAB
Dr. Agha Umer Daraz	Vice-Chairman MAB
Dr. Munira Borhany	Member
Dr. Shabniz Husain	Member
Dr. S.Shoukat Ali	Member
Dr. Kamran	Member
Dr. Kaleem Khan	Member

Administration

Umair Baig	Office Secretary
Arif Jamal	Head of IT
Ayaz Ali	Shift Incharge
Sidra	Finance
Ishrat	Receptionist
Sharukh Khan	Data Putter/Phlebotomist
Amna	Data Putter
Saira Sultana	Project Coordinator
Dr. Mushtaq Memon	Medical Officer
Dr. Rukhsanda	Physiotherapist
Mubeen Shah	Lab & Product Incharge
Muhammad Umair	Mufti Alam e Deen

Bleeding Disorder Community Groups

Jawwad Shahid	Youth Group Leader
Qurat ul Ain	Women Group Leader
Nargis Awan	Parents Group Leader

Focal Person

Dr. Arshi Naz	Hyderabad Division
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Thank You for Your Attention!



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