



ANNUAL REPORT 2018

A YEAR OF
ACCOMPLISHMENTS

HAEMOPHILIA PATIENTS WELFARE SOCIETY - RAWALPINDI

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PatientsWelfareSociety/

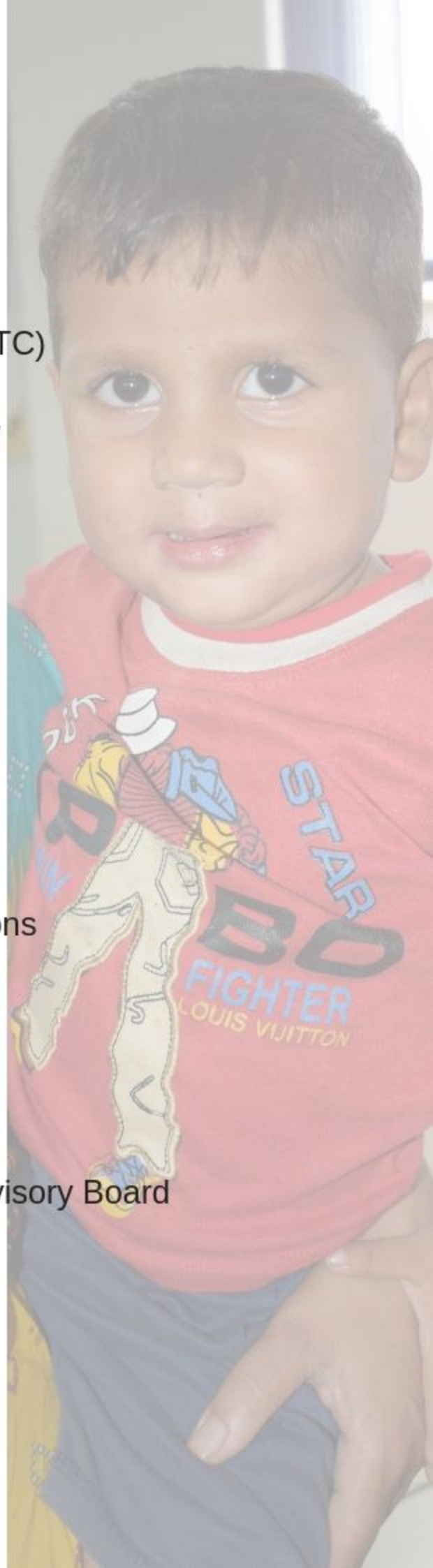
Tipu Road, Rawalpindi

hpwsrwp@gmail.com



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PRESIDENT
DR. MUNAWAR SHER KHAN

I have a feeling of great satisfaction on presenting the Annual Report 2018. It has been a year of many accomplishments, which are reflected in this report and could not have been achieved without the help of our various stakeholders, in particular the World Federation of Haemophilia and the Haemophilia Foundation Pakistan. However we are still facing many challenges not only related to the high cost of Factors, their non availability in Government Hospitals and in locating over 16,000 patients with inherited bleeding disorders who are not receiving any sort of treatment at all. Our plan for 2019 and beyond is to do our very best to spread awareness about Haemophilia and its treatment and last but not least to persuade the Government of Pakistan to establish Comprehensive Haemophilia Treatment centres at every Government hospital tehsil level and up. For this we require your prayers and support to make true the slogan of "Treatment for All".



DIRECTOR HTC
DR. TAHIRA ZAFAR

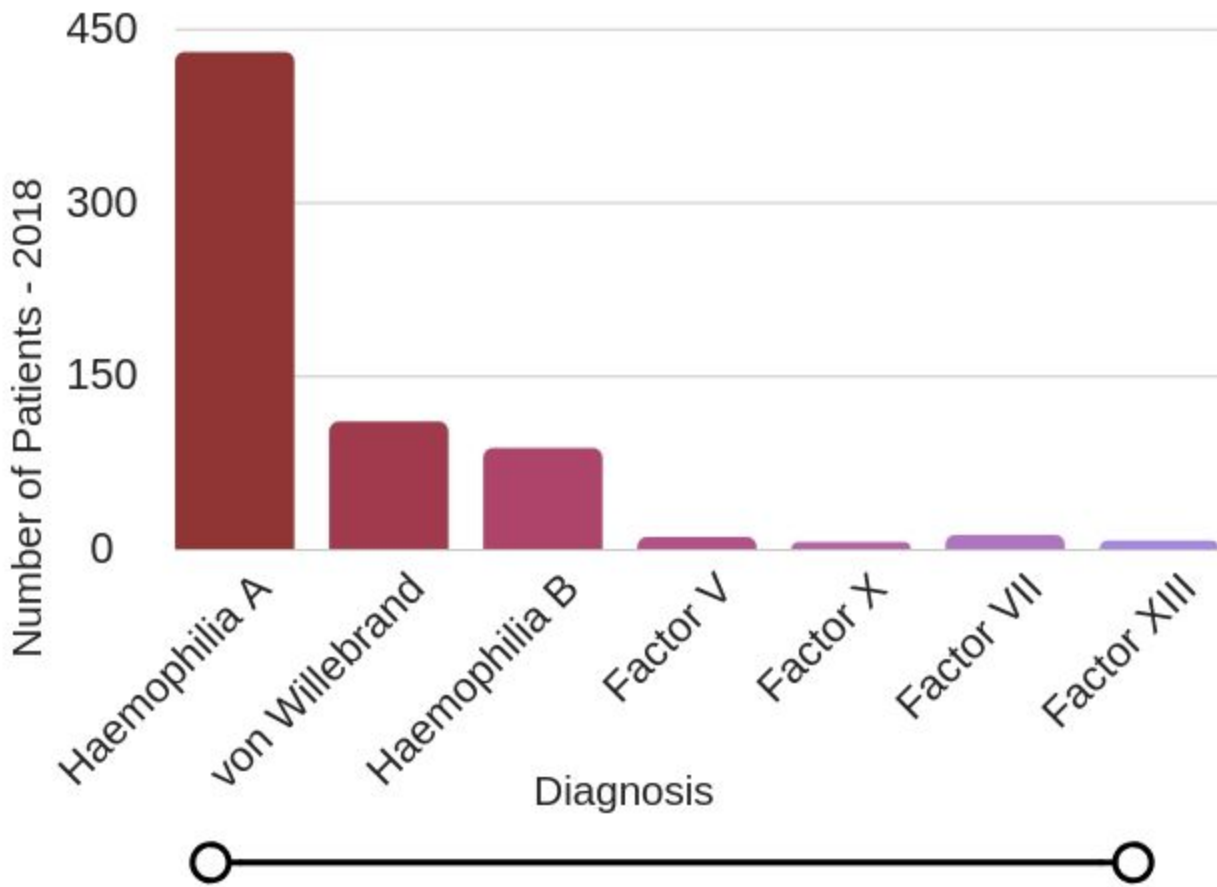
I am proud to celebrate making a difference in the lives of patients with inherited bleeding disorders (IBD's) in 2018. The accomplishments in the past year have been made possible by the support of our partners in care, our donors and our dedicated staff. I am extremely grateful to all of them for their help & support. My team & I, pledge to continue, on behalf of every child with IBD, to work to the best of our capabilities to improve their lives and achieve full physical & psychosocial development. I look forward to another exciting year!

Services Provided

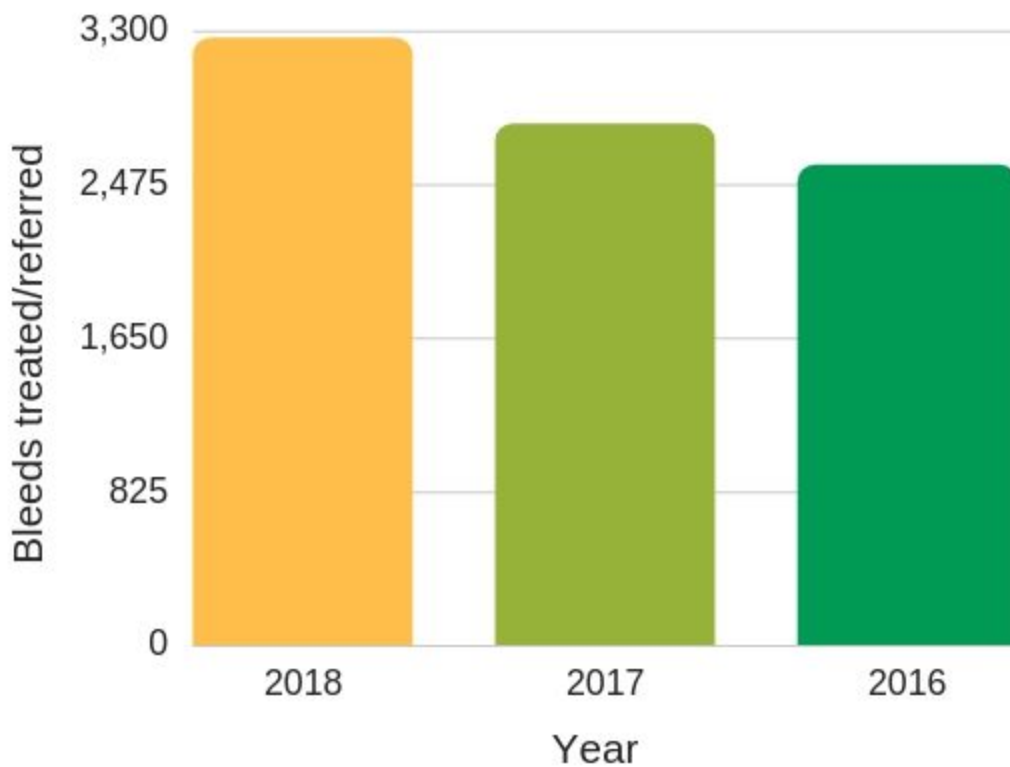


Free consultations by Medical Officer and Medical Advisory Board Specialists, Around the clock emergency coverage, Provision of Factors donated by World Federation of Hemophilia, Provision of purchased Factors at subsidized rates, Arranging admissions in Hemophilia Friendly Hospitals including Factor coverage for emergencies, surgical procedures and deliveries, Arranging ultrasound and gynecological follow ups either free or on subsidized rates, Coordination with Save One Life (SOL) for Sponsorships, Scholarships, Microenterprise Grants along with Factors from Project Share, Laboratory investigations at subsidized rates through an MOU with Armed Forces Institute of Pathology along with capacity building sessions for caregivers and patients on dealing with bleeds at home.

Total Patients



Bleeds Treated/Referred over the Years



MEETINGS



PSPOCON - AFIP
20-22nd April 2018



Dr Tahira met Prof Tuddenham at Royal Free Hospital to discuss gene therapy in our patients. September 2018



CMH Lahore - October 2018



FFP's in management of haemophilia & IBD's November 2018

The WBDR is here!

The newly launched WFH World Bleeding Disorders Registry (WBDR) is the only global registry collecting standardized clinical data on people with hemophilia from around the world.

Contact: wbd@wfh.org



Our HTC has become a part of World Federation of Haemophilia initiative of World Bleeding Disorder Registry .This will help improve care of our patients in future.

Our Miracle Babies!



Our patients, Nosheen & Shumaila both with Type 3 vWD, had normal delivery at Benazir Bhutto Hospital (BBH). Both were closely monitored throughout pregnancy with a clear written down plan for Factor support during delivery. The factors were provided by the HPWS-Rwp .There was no excessive bleeding during or after delivery and the babies appeared to be perfectly healthy .

LOW DOSE PROPHYLAXIS

LAUNCH-17th April 2018



This Project is supported by Factors donated by the World Federation of Haemophilia (WFH) through its Humanitarian Aid Program & shares its vision of preventing of disabilities in children with haemophilia in developing countries .The main objective is to see the impact on spontaneous bleeding in joints and psycho social health in our patients and the 6 monthly assessment has shown such a positive effect that there is no wonder there is 100 % compliance!

DONORS

Capt. Nasir Iqbal
Col. Syed Qamar ul Islam ®
Dr. Abdullah Naeem
Dr. Ahmed Fawad
Dr. Amir
Dr. Anam Nadir
Dr. Anwar Gul
Dr. Asif Zafar
Dr. Ayesha Junaid
Dr. Ghazala Saddat
Dr. Habiba Tariq
Dr. Imran
Dr. Kausar Warris
Dr. Mansoor Jan & Fehmida
Dr. Munawar Sher Khan
Dr. Nadeem Ikram
Dr. Nadia Mehmood
Dr. Nusrat Sharif
Dr. Sarah Zafar
Dr. Tahira Zafar
Dr. Zakia
Mr. Awais Shah
Mr. Abid Hussain
Maj. Gen. Parvez Ahmed ®
Maj. Gen. Suhaib Ahmad ®
I & I Welfare Trust
Mr. Shahid Waqas
Maj. Iftikhar Kiyani ®
Mr. Amir Rehan
Mr. Farrukh Hayat Khan
Mr. Fayyaz Ahmad
Mr. Hassan Raza
Mr. Inayat
Mr. Jahangir Khan
Mr. Khan Arif Masud
Mr. M. Saeed
Mr. M. Shabir
Mr. M. Sultan
Mr. Majid Khan
Mr. Mehboob

Mr. Mehmood Jan & Shahida
Mr. Nadeem Haider
Mr. Omar Sher Khan
Mr. Pasha & Naseem
Ms. Ros Cooper
Mr. Shahid
Mr. Shahid Hamdani
Mr. Shehzad & Parveen
Mr. Sheraz
Mr. Tasavur Rahman
Mr. Waqas Durrani
Mrs. Bilqees Hamdani
Mrs. Bina Naeem
Mrs. Farhat Bokhari
Mrs. Farrukh Hamdani
Mrs. Fehmida Mansoor
Mrs. Gauhar Tariq
Mrs. Iman Zaman
Mrs. Izza Azher
Mrs. Kanwal
Mrs. Khalida Rana
Mrs. Naila Israr
Mrs. Rehanna Bhutto
Mrs. Rozi Tabassum
Mrs. Shugufta Sajaad
Mrs. Tanvir Tahir
Mrs. Tariq Anwar
Mrs. Tehrim Zaman
Mrs. Uzma Azam
Mrs. Zahid
Ms. Abira Maheen
Ms. Fatima Masud
Ms. Fozia Parveen
Ms. Nighat Yasmeen
Ms. Saba Azim
Ms. Samina Malik
Sarhad Woolen Mills
Rear. Admiral Khan Masud Alam ®

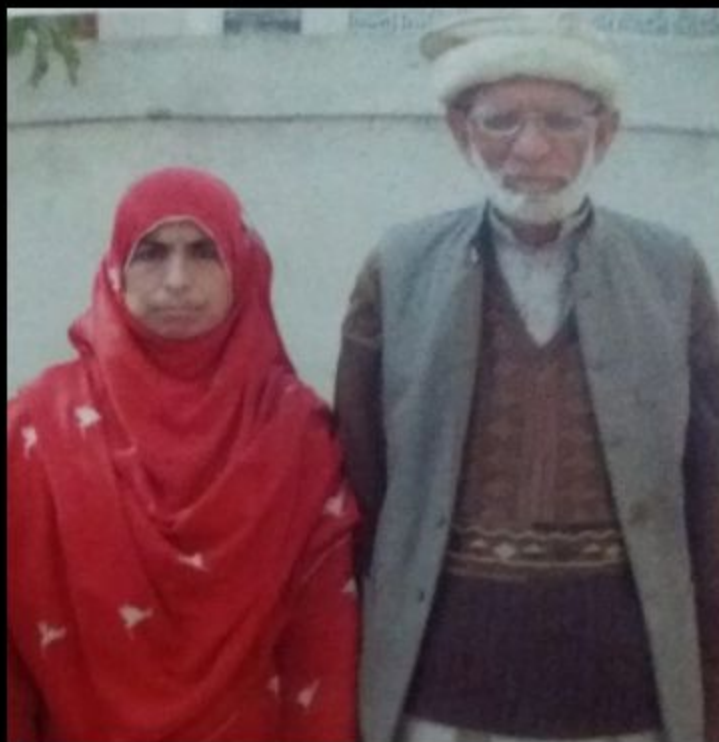
TOTAL AMOUNT DONATED

3,060,592/-

FRIENDS & DONORS



Personal Story



Ms. Nazia Kausar

I was told the first time I fell when I was a child, my blood didn't clot and kept on flowing as a result my parents were very worried. With the passage of time, multiple methods were adopted by doctors to help my blood flow stop.

As I grew up, every time I needed blood a family member would donate blood for me. Eventually my father took me Holy Family Hospital and then my diagnosis was given and my parents found out I was a hemophiliac by birth. As time passed I found out I was in fact a patient of VWD. I met Dr. Tahira at Sundas Foundation, Gujranwala whilst getting treatment. After meeting her I started getting solutions to my problems as she felt my pain the same way I felt it. After getting inspired by her my father Mr. Mushtaq Ahmad also joined her NGO and started serving us hemophiliacs with full enthusiasm and we gave them our blessings continuously.

SOL Success Story



Mr. Ali Raza Marchal

SOL Scholarship

I would express my heartiest gratitude for your cooperation HPWS and support in the form of SOL scholarship from Save One Life. The scholarship granted to me last year was extremely beneficial for me as it enabled me to afford my dues of MS. With the grace of Lord. But along with my efforts, the other factor which contributed in my success is SOL scholarship & Society. Being a hemophilic and belonging to a middle class, it was troublesome for my father to bear my educational expenses.

I chose University of Azad Jammu & Kashmir because I really enjoyed the size of the campus and it's near to my home. I enrolled in a master's degree in computer science because the job availability after graduating would be great, and after completing MS I wish to get admission in PHD.

SEMINAR ON PSYCHOSOCIAL ISSUES IN PATIENTS WITH HAEMOPHILIA - 17th March 2018

Courtesy of NNHF (PK6)



It is widely accepted that inherited bleeding disorders can have negative effects on the ability of a person effected to become a productive and participating member of society. The aim of HPWS Rwp is to combat this notion and help those with Inherited bleeding disorders and lack of clotting Factors to not only cope with normal stress but the extra burden of their disease which can create various types of challenges such as marital problems, school problems, financial problems, and job worries. Women with bleeding disorders have to face even more difficulties as marriages within families is the norm and they often stay single as no one is willing to take on the responsibility of caring for them , while and at the same time many come from conservative families and cannot work and become financially independent.

Funded by Nova Nordisk Hemophilia Foundation through the Hemophila Foundation Pakistan and the generosity of Mr. Zamarrud Khan Patron in Chief, Pakistan Sweet Homes, we held a day-long exercise on stress management for the members of our Chapter and their families.

FROM 809-D TO TIPU ROAD

A better facility & treatment centre has been established where there is a separate room for consultants, treatment, administration etc. This has led to prompt delivery of care on time. Another addition in this new setup is the children's play room which has been an incentive for them to come when needed and get their factors without crying. The conference room is adequate space for awareness sessions & meetings.



Caring for the Uncared (Development Grant Project)

Courtesy of: World Federation of Hemophilia

Implementation by: HPWS Rwp with the help of HFP & other chapters

Introduction: Pakistan as per the international statistics has around 22,000 patients with Hemophilia, but currently as per the Hemophilia Foundation - Pakistan [NMO]'s national registry, there are only approximately 2,000 identified patients and the rest have to be identified. Many activities will be held during this Project and through these steps, we hope to trace and then test these individuals for bleeding disorders and once diagnosed, they can be registered and given proper treatment.

Project Goals & Objectives: To trace & diagnose individuals who are suspected to have Hemophilia or other bleeding disorders, collect data which can be utilized for advocacy with government and research, create awareness among the Patients, their families, HCPs, and the masses about the disease & genetics of the disease and intermarriages.

Expected Result: To diagnose up to 500 new patients by the end of the project, consolidate the data for research and advocacy & sensitize our existing & future stakeholders.

WORLD HAEMOPHILIA DAY CELEBRATIONS - APRIL 2018





WFH 2018 WORLD CONGRESS

GLASGOW, SCOTLAND • MAY 20-24, 2018



The World Federation of Hemophilia (WFH) World Congress is held every two years & is the largest meeting for the bleeding disorders community worldwide. From May 20-24 more than 5000 people traveled from all corners of the globe to the Glasgow and attended this mega event. Dr. Munawar Sher Khan (President), Dr. Lubna Zafar (VP-I) & Dr. Tahira Zafar (Director HTC) participated in the Congress along with a delegation of the Hemophilia Foundation Pakistan (HFP) which included Persons with Inherited Bleeding Disorders and Physicians under the leadership of President-HFP/NMO.

OPEN HOUSE - 29TH SEPTEMBER 2018



Annual General Meeting 2018



The meeting started with the recitation of the Holy Quran by Mr. Sajid Nawaz, a patient, & a welcome address by Dr. Tahira Zafar, who introduced the Society to Members of the Board of Governors, Medical Advisory Board, Executive Board, Youth Group, Women's Group, Save One Life beneficiaries, Staff, Patients, Donors & Volunteers. Dr. Munawar Sher Khan, President of the Society then presented the Annual Report 2018 & the society's audit report 2017/2018 by Mr. Faisal Latif & Co. The electorate present approved the Annual & Audit Report.

Patient's presented their life stories and discussed how they have overcome the hurdles faced. The AGM was concluded by a speech given by the Chief Guest Maj. General (Retd) Suhaib Ahmed -President, Pakistan Thalassemia Welfare Society, CEO GRC & a professor at Riphah University & closing remarks by the Guest of Honor General (Retd) Pervaiz - Consultant Hematologist at Quaid-E-Azam International Hospital and Ex-Comdt AFIP/AFBMTc followed by distribution of shields by Executive Board Members. During the AGM the children were entertained separately by Ms. Abira Maheen. The latter part of the day was patient oriented in which an in depth open discussion was conducted by Medical Advisory Board Consultants. This was followed by Save One Life's (SOL) sponsorship fund distribution for its beneficiaries. HPWS RWP extends its gratitude to all those who attended and especially Mr. Zamarud Khan, Patron-In-Chief - Pakistan Sweet Homes, Member - BOG's HPWS RWP for hosting the event.

AFFILIATIONS

Thank You for your Support!



WFH



AUDIT REPORT 2017-2018

PAKISTAN HAEMOPHILIA PATIENTS WELFARE SOCIETY-RWP
BALANCE SHEET
AS AT 30TH JUNE 2018

	Note	2018 Rupees	2017 Rupees
ASSETS			
Non Current Assets			
Property, plant and equipment	5	419,954	228,060
Investment-Nafa Securities		2,506,052	2,540,604
		2,925,996	2,766,664
Current Assets			
Advance and other receivables	6	30,077	91,324
Cash and bank balances	7	3,761,469	1,889,989
		3,791,546	1,981,312
ACCRUED LIABILITIES			
Accrued and other payable	8	25,000	25,000
NET ASSETS		<u>6,692,152</u>	<u>4,722,976</u>
REPRESENTED BY			
General reserves	9	6,692,152	4,722,976
TOTAL LIABILITIES		<u>6,692,152</u>	<u>4,722,976</u>

The annexed notes form an integral part of these financial statements.

Hamid Raza Khan
PRESIDENT

Board of Governors



Maj. Gen Parvez Ahmed®



Dr. Fazle Hadi



Mr. Zamarrud Khan



Prof. Asif Zafar Malik



Mr. Anjum Riaz Malik



Mrs. Samina Manzar



Dr. Mansoor Jan



Mrs. Fahmida Jan



Dr. Riaz Malik



Mrs. Shama Riaz Malik

Medical Advisory Board



Dr. Tahira Zafar



Dr. Lubna Zafar



Dr. Nadeem Ikram



Dr. Riaz Sheikh



Prof. Khalid Aslam



Dr. Humaira Bilquis



Dr. Irum Naeem



Prof. Naeem Zia



Dr. Zahida Ahmed



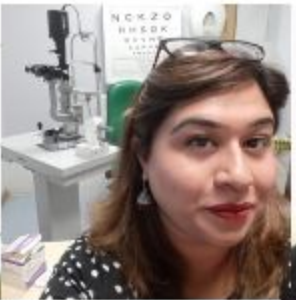
Dr. Ayesha Farid



Dr. Qasim Ali



Dr. Farkhanda Nazli



Dr. Sarah Zafar



Dr. Nauman Maqbool

Management



Dr. Munawar Sher Khan
President



Dr. Lubna Zafar
VP I



Mr. Fazal E Qayyum
VP II



Mr. Atta Mohammad
General Secretary



Mr. Khawar Yasin
Treasurer



Dr. Tahira Zafar
Director HTC



Dr. Nadeem Ikram
Information Secretary



Ms. Rabia Saleem
Joint Secretary



Dr. Sarah Zafar
Member



Ms. Fozia Parveen
Member



Mr. Uzair Hussain
Member



Mr. Hassan Raza
Member



Ms. Abira Maheen
Member



Mr. Shahzaib Malik
Member



Mr. Ali Raza Marchal
Member

