YEAR 2023

ANNUAL REPORT 2023

HEMOPHILIA WELFARE SOCIETY KARACHI

NON-PROFIT PATIENT-BASED SINGULAR ORGANIZATION AND INCLUSIVE PLATFORM OF HEMOPHILIA BLEEDING DISORDER COMMUNITY

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ABOUT US

THE HEMOPHILIA WELFARE SOCIETY KARACHI (HWSK) REGISTERED NON-PROFIT PATIENT-BASED ORGANIZATION, IS THE SINGULAR ORGANIZATION AND INCLUSIVE PLATFORM FOR BLEEDING DISORDER PATIENTS & PARENTS IN SINDH, PAKISTAN. AFFILIATED WITH WORLD FEDERATION OF HEMOPHILIA AND PARTNER WITH HEALTH DEPARTMENT GOVT. OF SINDH AND ALSO REGISTERED WITH THE SINDH TECHNICAL EDUCATION BOARD TO TRAIN HEALTHCARE PROVIDERS TO LEARN AND MANAGE HEMOPHILIA BY PROVIDING A DIPLOMA IN TRANSFUSION MEDICINE.

WE ARE AS THE HEMOPHILIA BLEEDING DISORDER COMMUNITY COMMITTED TO CATERING TO THE NEEDS OF INDIVIDUALS GRAPPLING WITH HEMOPHILIA BLEEDING DISORDER CONSTANTLY STRIVE TO PROVIDE A VITAL LIFELINE AND STATE-OF-THE-ART TREATMENT AND FACILITIES AS WELL AS EDUCATION EMPOWERMENT & REHABILITATION THROUGH VARIOUS GROUPS OF WOMEN, YOUTH, AND MEDICAL ADVISORY BOARD, EXECUTIVE COMMITTEE UNDER THE ONE ROOF IN OUR HEMOPHILIA TREATMENT CENTERS.

BEFORE HWSK, INDIVIDUALS WITH HEMOPHILIA AND OTHER BLEEDING DISORDER PATIENTS AND THEIR FAMILIES RELIED ON ALTERNATIVE AND INSUFFICIENT TREATMENT FROM VARIOUS BLOOD BANKS AND THALASSEMIA CENTERS, WHICH WERE NOT SUITABLE, PLACES FOR HEMOPHILIA TREATMENT AND CARE AS PATIENTS COULD ONLY DEPEND ON RECEIVING SUBSTANDARD SCREENED BLOOD COMPONENTS WHICH LED TO TRANSFUSION-RELATED VIRUSES, CONTRIBUTING TO A HIGHER MORTALITY RATE INCREASING TARGET JOINTS AND DEFORMITIES.

THEY WERE ALSO UNABLE TO PROVIDE MONITORING, COUNSELING, PROPER DIAGNOSIS, AND TREATMENT, THIS CONDITION WAS POSING A SIGNIFICANT CHALLENGE TO THE DAILY LIVES OF PATIENTS, CONTRIBUTING TO A CONSIDERABLE HEALTH BURDEN MARKED BY DISABILITY-ADJUSTED LIFE YEARS AND PREMATURE MORTALITY, STEMMING FROM BOTH INTERNAL AND EXTERNAL BLEEDS.

WE ARE REGISTERED WITH

- Social Welfare Department Govt of Sindh
- Sindh Health Care Commission
- Sindh Charity Commission
- FBR
- World Bleeding Disorder Registry (WBDR) WFH
- Economic Affairs Division (EAD)
- Pakistan Centre of Philanthropy (PCP)
- Sindh Technical Board of Education

OUR HEMOPHILIA TREATMENT CENTERS AND INSTITUTION

- Hemophilia Treatment Center Nazimabad Karachi (Head Office)
- Hemophilia Satellite Treatment Center - Mirpur Khas
- Hemophilia Satellite Treatment Center - KhairPur (Gambat)
- HWSK Institute of Transfusion Medicine & Blood Related Disorder Nazimabad(KHI)

AFFILIATION & COLLABORATION

- WORLD FEDERATION OF HEMOPHILIA (WFH)
- Health Department Government Of Sindh
- SINDH BLOOD TRANSFUSION AUTHORITY (SBTA)
- INDUS HOSPITAL
- GAMBAT INSTITUTE OF MEDICAL SCIENCES (GIMS)
- Liaquat University of Medical & Health Sciences (LUMS)
- PATIENT WELFARE ASSOCIATION (PWA)
- HUSSAINI BLOOD BANK
- NATIONAL INSTITUTE OF BLOOD DISEASE & BONE MARROW TRANSPLANTATION (NIBD)
- JINNAH POSTGRADUATE MEDICAL CENTRE (JPMC)
- REGIONAL BLOOD CENTER (RBC)
- Dow Medical & Health Science (DOW)
- HEMOPHILIA FOUNDATION (Pakistan)
- Hemophilia Patient Welfare Societies Lahore, Rawalpindi, Peshawar & Balochistan

MESSAGE OF THE CEO

Dear Members, Stakeholders, and Mission Partners.
I hope this message finds you in good health and high spirits. As we come together to reflect on the accomplishments of the past year, I am both honored and delighted to share the annual progress report of the Hemophilia Welfare Society. Our journey, marked by challenges and triumphs, has been guided by a collective commitment to advancing treatment, care, education, empowerment, and awareness for those affected by hemophilia.
In 2023, we expand our treatment center and empower healthcare providers through the Transfusion Medicine Training Institute.
Our efforts were recognized by the President of the World Federation of Hemophilia, fueling our passion to continue our mission.
I am thrilled to report that our fruitful efforts in the previous year led to the expansion of our treatment center. This expansion allowed us to extend our care and support to a greater number of patients, making a tangible impact on the lives of individuals grappling with hemophilia. It is a testament to the dedication and passion of our team and the unwavering support from our community.
In our pursuit of excellence, we established a Transfusion Medicine Training Institute to empower healthcare providers with the knowledge and skills essential for effective hemophilia bleeding disorders management. By investing in education, we are contributing to a future where every healthcare professional can provide top-notch care to those in need.
Notably, we've been recognized as the first Hemophilia Welfare Society in Pakistan and have successfully advocated for 06 children PwBDs prophylaxis treatment inclusion in the health budget of Govt. of Sindh marking a significant step forward.
Thank you for your unwavering support as we continue to foster hope and create positive change.

MESSAGE OF THE PRESIDENT

In the name of Allah, the Most Gracious, the Most Merciful,
With gratitude to Allah, I am honored to share the strides of our organization in 2023. We remain steadfast in our commitment to providing exceptional facilities and a dignified environment for those afflicted by hemophilia.
Through the grace of Allah, we have significantly enhanced our facilities to meet the evolving needs of our patients, ensuring they receive unparalleled care within a nurturing environment.
Our mission, guided by Islamic principles, places great emphasis on the dignity and well-being of every individual
In 2023, we redoubled our efforts to create spaces that nurture emotional and psychological healing alongside medical treatment. We humbly acknowledge that our achievements are only made possible through the generosity of our supporters, who are a blessing from Allah.

DR. MUNIRA BORHANYY
MBBS, MCPS, FCPS, FRCP (EDIN.), FRCPATH (UK).

I am pleased to share the latest progress report from the Hemophilia Welfare Society, Karachi. Over the past year, we have made significant strides in our mission to enhance the lives of those affected by hemophilia and other bleeding disorders. Our outreach programs have reached more individuals, providing crucial education and support. Additionally, advancements in treatment options have been explored, offering hope for improved quality of life. I commend our dedicated team and patients for their unwavering commitment to our cause. Together, we continue to make a meaningful difference in the lives of those with hemophilia. Thank you for your ongoing support and we look forward to work with you.

PATIENT REGISTRY AND STATISTICS

REGISTRY BACKGROUND

To tackle the challenge of bleeding disorder countries should establish national registries for patients with hemophilia, either administered centrally by a national authority or through multinational collaborations. Before the advent of the National Patient Registry of Hemophilia Foundation and the World Bleeding Disorder Registry (WBDR) of WFH, there wasn't any source available that could be treated as a reference point for Bleeding Disorder Patients in Pakistan.

But now, the World Federation of Hemophilia's World Bleeding Disorders Registry offers a standardized platform for hemophilia treatment centers worldwide to collect and monitor patient data, aiding in treatment tracking and improving clinical practices. These registries compile data on treatment, outcomes, and quality of life, enabling analysis of care standards, resource planning, and identification of treatment disparities. They also enhance understanding of hemophilia variations, care patterns, and resource utilization. However, it's crucial to prioritize data privacy and ethical considerations, ensuring patients or their guardians comprehend the registry's purpose

PREVALENCE OF HEMOPHILIA

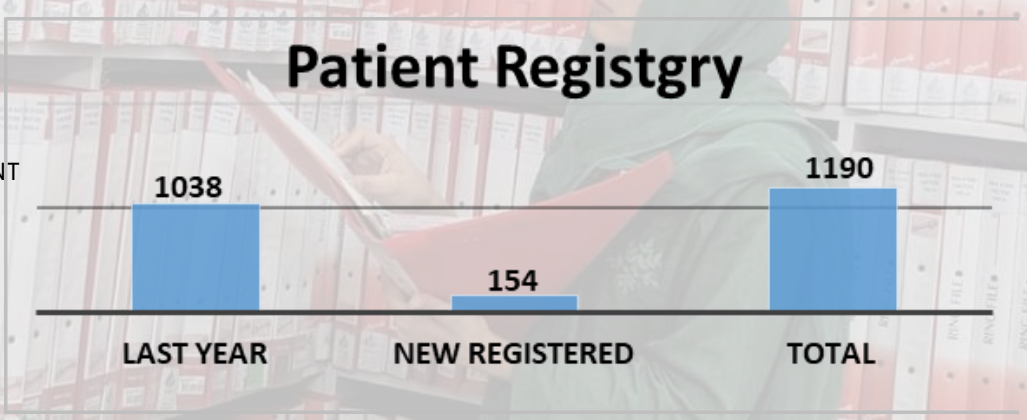
ACCORDING TO THE ANNUAL GLOBAL SURVEY **2022, 17.1/100,000 MALES** FOR ALL **HEMOPHILIA A 6.0/100,000 MALES** FOR **SEVERE HEMOPHILIA A 3.8/100,000** MALES FOR ALL **HEMOPHILIA B 1.1/100,000 MALES FOR SEVERE HEMOPHILIA B**

THE CURRENT PREVALENCE OF THE DISEASE IS FOR **HEMOPHILIA –A 24.6/100,000**

HEMOPHILIA BLEEDING DISORDER PATIENTS REGISTRY

THE HWSK REGISTRATION IS LINKED TO THE NATIONAL HEMOPHILIA REGISTRY WORLD BLEEDING DISORDER OF WFH ONLINE REGISTRY PORTALS, AND OUR HEMOCLICK SOFTWARE WHICH IS FURTHER LINKED TO THE COUNTRY-SPECIFIC WFH REGISTRY AND IS UPDATED EVERY YEAR GLOBALLY IN CASE OF:

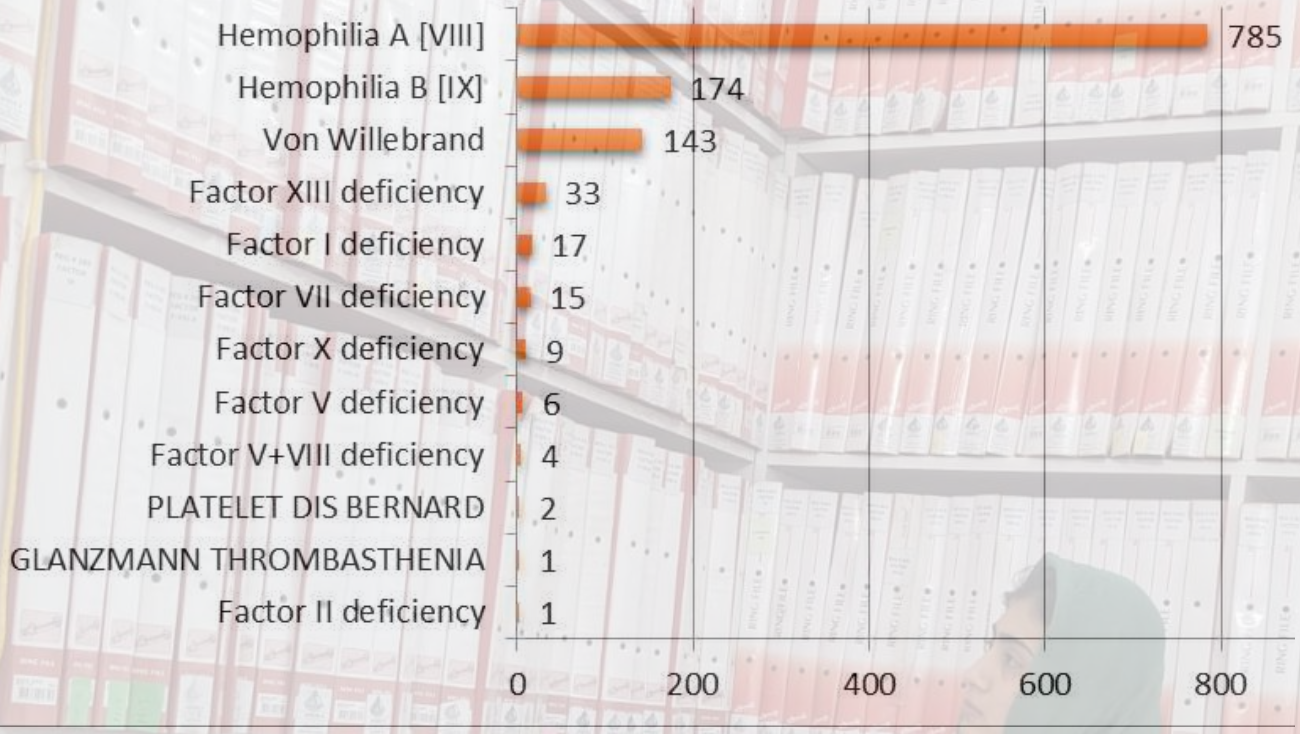
- MIGRATIONS
- MORTALITY
- DUPLICATIONS
- DEMOGRAPHICS
- QUALITY OF LIFE MEASUREMENT
- AGE BY GROUP
- INFECTIOUS DISEASES
- DISABILITY

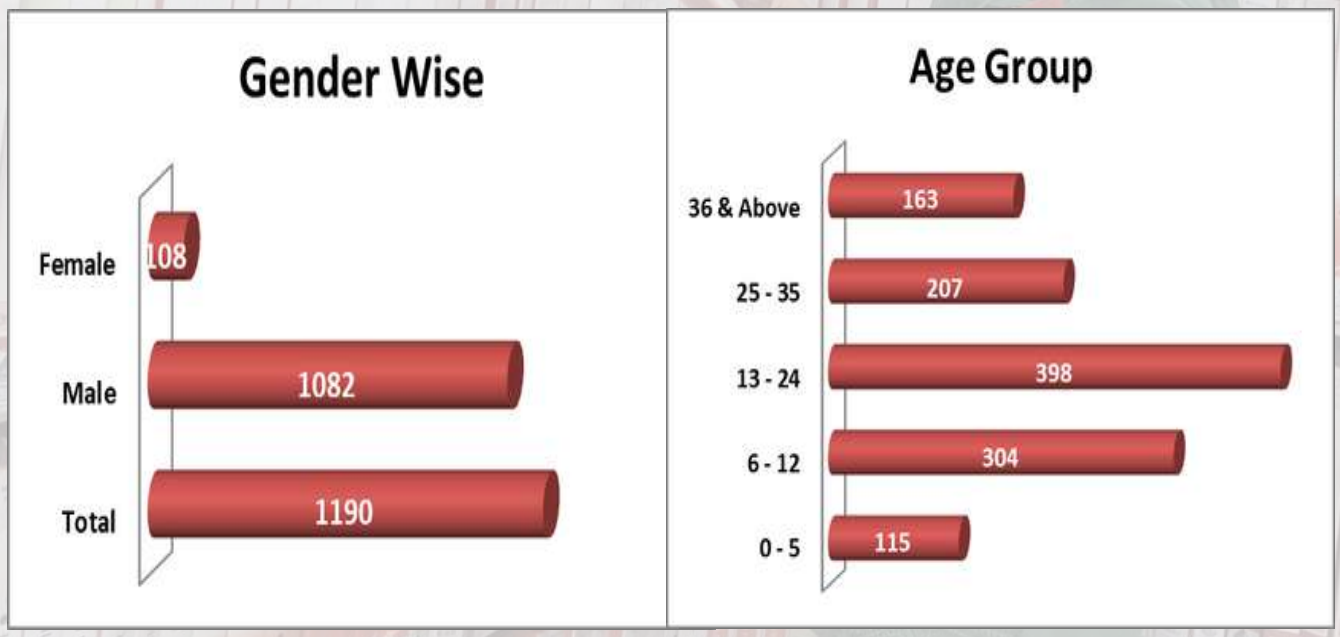


Last year, we had 1038 patients, and with 154 new enrollments, the total became 1190. To calculate the percentage growth in patients, we can use the formula:

14.64%

The number of patients increased by 14.64 percent.

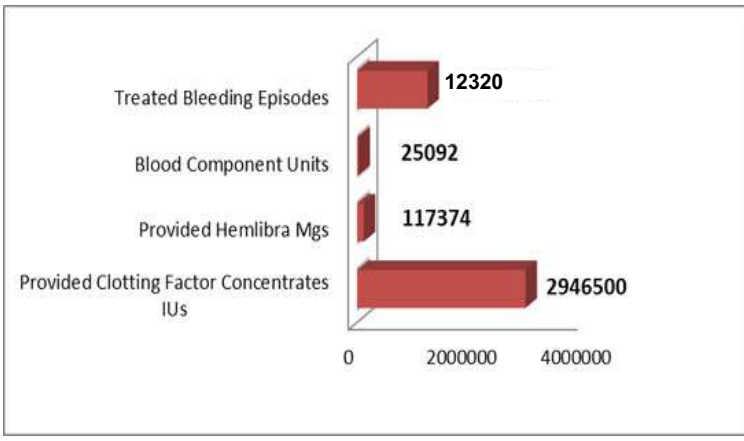

Hemophilia A [VIII]
785
Hemophilia B [IX]
174
Von Willebrand
143
Factor XIII deficiency
33
Factor I deficiency
17
Factor VII deficiency
15
Factor X deficiency
9
Factor V deficiency
6
Factor V+VIII deficiency
4
PLATELET DIS BERNARD
2
GLANZMANN THROMBASTHENIA
1
Factor II deficiency
1
0
200
400
600
800


Gender Wise
Female
108
Male
1082
Total
1190
Age Group
36 & Above
163
25 - 35
207
13 - 24
398
6 - 12
304
0 - 5
115

TREATMENT PROVISION IN 2023

Pakistan is a developing country in which the management of Hemophilia is still providing treatment of the stone-age era in public & private hospitals. Unfortunately in Pakistan, Hemophilia is considered as an Orphan Disease in the Health Sector at both the Federal and Provincial Levels. In the Public Health Sector, Hematology Departments are dysfunctional and are unable to provide Hemophilia medicines and diagnosis and other required facilities and treatment provisions like On-Demand Prophylaxis or any other advanced medications that are being provided in our neighboring countries.

Hemophilia medicines are not included in the federal or provincial health budget nor there are any policies developed to tackle this inherited disease. Hemophilia medicines a very costly medicines therefore patients do not possess the buying power required to buy these medicines, the estimated range for the treatment of each patient per year starts from **RS. 3.2 Million** To **RS. 15 Million.**



TREATMENT PROVISIONS SOURCES:

WORLD FEDERATION OF HEMOPHILIA (WFH) HUMANITARIAN AID

The WFH Humanitarian Aid Program has worked with the national member organization (NMO) and hemophilia welfare societies in Pakistan over many years to raise the level of care provided to PWBDs in the country. This long-term support has come in the form of education and donated treatment products. The decades-long commitment of the Program has been instrumental in giving the local community the self-confidence to build a better support infrastructure for PWBDs.

Since 2015, over 62 million IUs of clotting factors have been donated to Pakistan. Nearly 12 million IUs of factor—and nearly 500,000 mg of non-factor replacement therapy.

TREATMENT PROVISIONS BY WFH

The World Federation of Hemophilia Humanitarian Aid programs like On-Demand, Low Dose Prophylaxis Treatment & Hemlibra Prophylaxis is a vital treatment lifeline source for 3500 out of 25,000 Hemophilia patients living in Pakistan including 1190 registered patients in Sindh province.

ON DEMAND:

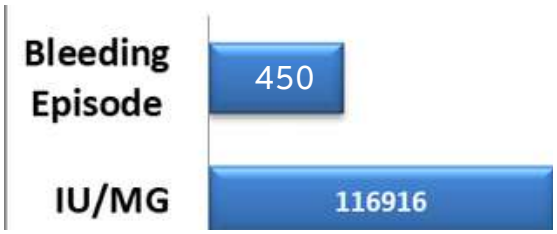
HWSK makes sure that there is support available whenever they need it for 70 to 80 bleeding episodes every day. Our goal is to improve the lives of those with hemophilia by providing timely and effective assistance and taking care of their unique needs.

LOW DOSE PROPHYLAXIS:

Currently, 25 children under 12 years of age out of 419 total hemophiliac children are enrolled in the LDP program. The purpose of this program is to provide treatment twice weekly to keep blood clotting factor levels steady, protecting joints from physical injury. They are getting monthly treatment to prevent their target joints and deformities to ensure quality of life.

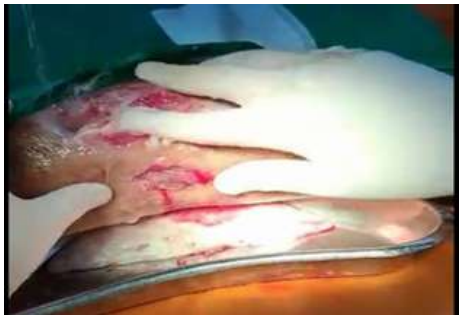
HEMLIBRA PROPHYLAXIS THERAPY PROGRAM BY WFH:

Hemlibra prophylaxis is a highly advanced game-changer treatment therapy. Currently, 38 patients out of 785 are enrolled in the Hemblibra prophylaxis program of WFH. HEMLIBRA is a high-cost which is treatment range starting from **PKR 300,000 - 1200,000** /month prescription medicine used for routine prophylaxis to prevent and reduce the frequency of bleeding episodes in the daily routine life of Hemophilia Factor VIII Patients.



SUCCESS CASE THROUGH WFH SUPPORT:

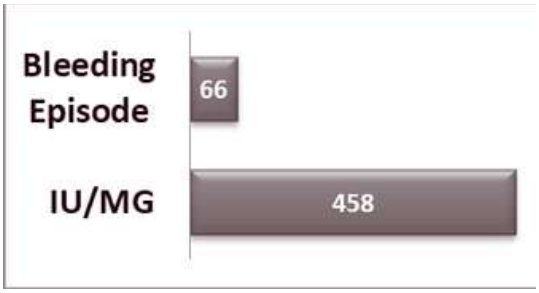
patient X, afflicted with Hemophilia A (Factor level 5%), endured persistent pain and swelling in the right knee joint, ultimately diagnosed as a knee abscess. Collaborating with Orthopedic Surgeon Dr. Shaukat, HWSK conducted the drainage procedure. Notably, both pre and post-surgery, the World Federation of Hemophilia's Humanitarian Aid stepped in, furnishing 40.5 Million IU's clotting factor concentrates crucial for facilitating recovery.



GOVT. OF SINDH

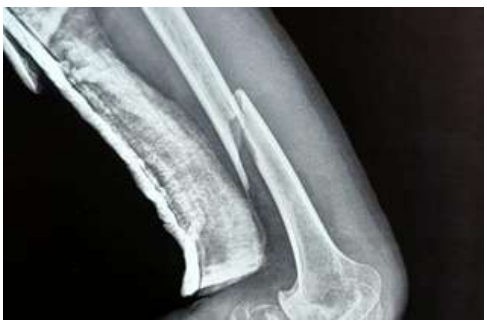
For the first time in Pakistan's history of any provincial health budget, Govt. of Sindh has allocated the advanced medicine of prophylaxis treatment to **06 out of 419** children under 12 years in the Annual Health Budget through the support of the Secretary Sindh Blood Transfusion Authority, Dr. Durenaz Jamal, Health Minister, Dr. Azra Fazal Pechuho.

06 kids under 12 years old are also enrolled with the support of a Sindh Government Grant in aid support of a 409. These total 06 patients are very lucky into Factor VIII Registered Patients in such advanced game-changer treatment. Each patient costs 36 Lacs/year. 403 patients under 12 years old remain and deserve this amazing life changer treatment for hemophilic patients

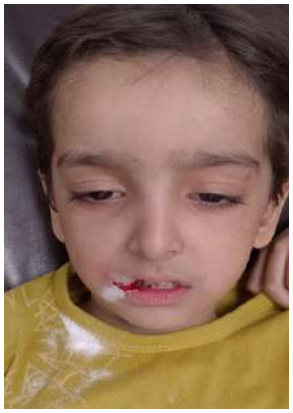


SUCCESS STORY ACHIEVED WITH GOVERNMENT SUPPORT PROVISIONS

Bilal, a 19-year-old with severe Hemophilia A from rural Sindh, required urgent left femur fixation surgery due to bone breakage resulting in profuse bleeding. Despite a positive inhibitor test, his procedure required 45 vials of 1mg Factor VII costing PKR 6.3 million as bypassing agents, the Health Department of the Govt., led by Minister of Health Dr. Azra Pechuho and Dr. Faiz Ali Mangi, supported the initiative, marking the first provincial-level effort to raise awareness and allocate funds for clotting factor concentrates.



TREATMENT PROVISION THROUGH BLOOD COMPONENTS (CRYOS & FFPS)

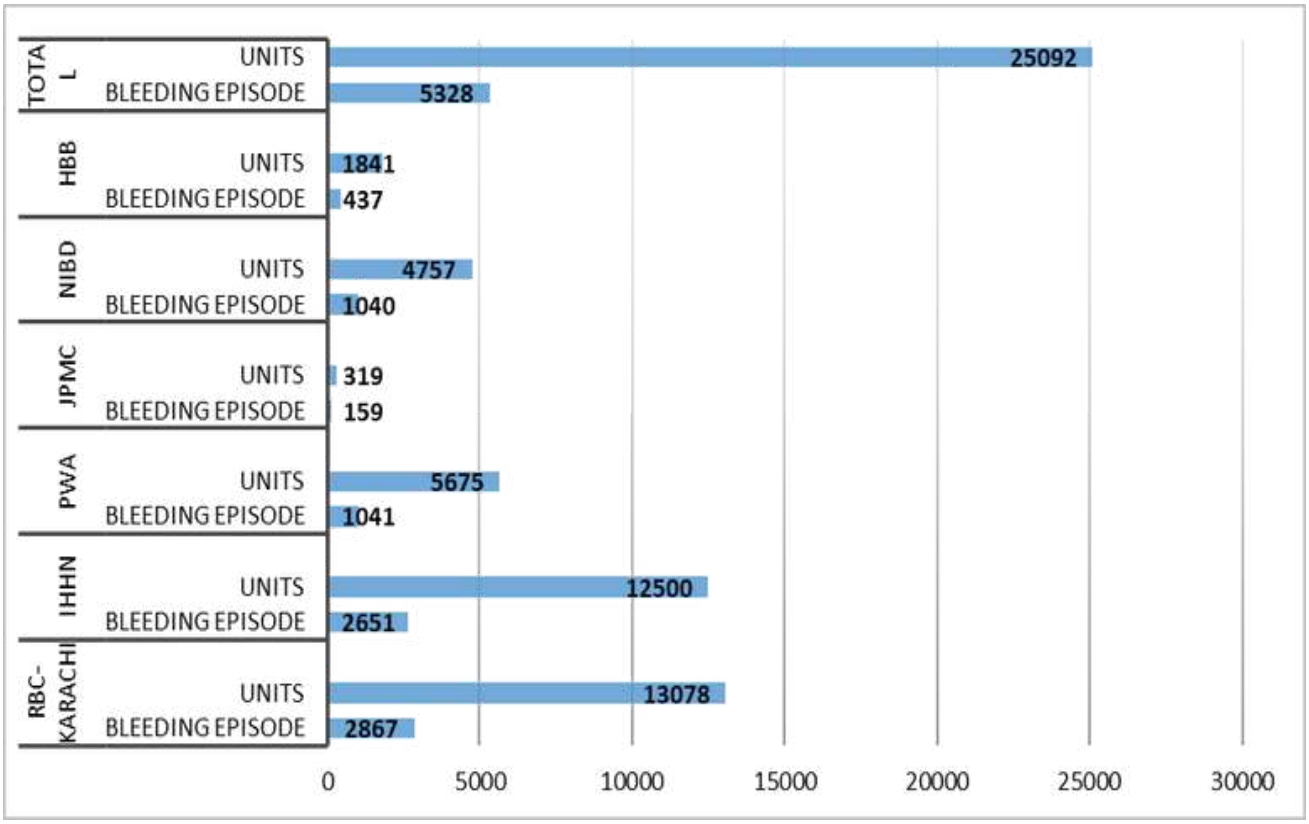


The reality of Hemophilia treatment in Pakistan is that approx.86% of hemophilia & bleeding disorder patients rely on blood components, for this purpose to ensure this treatment

HWSK collaborates with different organizations to ensure the availability of Blood Components like Cryoprecipitate & Fresh Frozen Plasma to deal with patient bleeding episodes.

The HWSK has also been able to ensure treatment through Blood Components (Cryos & FFPs) that help us to fulfill treatment gaps through effective collaboration with Sindh Blood Transfusion Authority and Health Department Govt. of Sindh's recognized and regulated Blood Institutions which include, Regional Blood Center- Karachi, Indus Hospital, and Healthcare Network, Patient Welfare Association, Husaini Blood Bank, Jinnah Post-Graduate Medical Center, National Institute For Bleeding Disorders and many more.

This effort would not have been possible without the undying support of the Sindh Blood Transfusion Authority under the directorship of Dr. Durenaz Jamal. HWSK appreciates the support of Dr. Durenaz Jamal and keeps it in the highest regard as without SBTA's support we would not have been able to cater to our treatment gaps.



EDUCATION & EMPOWERNMENT THROUGH THE SAVE ONE LIFE (SOL) PROGRAMS

SOL PROVIDED IN 2023 34.8 MILLION DIRECT FUNDS TO OUR PATIENTS

SOL BENEFICIARY:

Save One Life (SOL) is a beacon of hope for patients worldwide with bleeding disorders. Through diverse funding initiatives, SOL supports 23 beneficiaries from the Hemophilia Welfare Society Karachi's patient community, easing educational expenses. Backed by Laurie A. Kelly's support, SOL empowers recipients and fosters a brighter future. Their impact extends globally, catalyzing positive change in communities.

SOL MICRO-ENTERPRISE GRANT (MEG):

The Micro-enterprise program is a transformative initiative empowering deserving patients to establish their businesses with direct support from sponsors. Beyond providing financial assistance, this innovative program nurtures entrepreneurial spirit, fostering autonomy and dignity. By equipping individuals with tools to create and manage businesses, it becomes a catalyst for lasting change, breaking dependency cycles, and fostering economic empowerment within the community.

SOL SCHOLORSHIP:

The SOL Scholarship program follows a distinct application procedure tailored to applicants aged 25 and above. It is important to note that eligibility for this scholarship is not determined solely by age; rather, it becomes a relevant consideration only once an individual has reached university or college level. Until then, prospective candidates are not eligible to apply for sponsorship. The scholarship serves as a beacon of support for those pursuing higher education, emphasizing that the age bracket becomes a key factor only during the university or college years. This nuanced approach ensures that deserving individuals are allowed to access educational sponsorship at the appropriate stage of their academic journey.

WFH DELIGATION VISIT

The World Federation of Hemophilia (WFH) is a non-profit organization dedicated to improving and sustaining care for people with inherited bleeding disorders around the world. WFH works in partnership with healthcare providers (HCPs), governments, and our global network of national member organizations (NMOs) in 147 countries. WFH provides NMOs and healthcare providers with the knowledge and tools they need to identify, support, and treat people living with bleeding disorders in their communities while promoting global advocacy and collaboration to achieve our common goals.

As a hereditary disease, hemophilia can affect multiple children in a family, increasing the challenges of parenting substantially—especially in a developing nation. The World Federation of Hemophilia aims to support emerging nations so that they can create self-sustaining support frameworks for people with bleeding disorders (PWBDs). This is one through endeavors on multiple fronts, such as the WFH PACT Program,

The WFH Twining Program, many country programs, and the WFH Humanitarian Aid Program. This is the only way to help build a supportive healthcare infrastructure that ensures that young families can raise their children without the stress and hardship that comes with a child or children who have an untreated—and even, all too often, an undiagnosed—condition.

INAUGURATION OF INSTITUTE OF TRANSFUSION MEDICINE BY PRESIDENT OF WFH

The Hemophilia Welfare Society Karachi organized a Stakeholder's Solidarity Seminar on Hemophilia and Bleeding Disorders in Karachi, featuring Mr. Cesar Garrido, President of the World Federation of Hemophilia, as the chief guest. Attendees included Rana Saifi, Dr. Phillipe from WFH, and Dr. Faiz Ali Mangi from the Health Department of the Sindh Government. The seminar attracted a diverse audience, including government officials, medical professionals, representatives from nonprofit organizations, pharmaceutical companies, and members of the media.

Mr. Cesar Alejandro Garrido D, President of the World Federation of Hemophilia (WFH), along with a delegation including Ms. Rana Saifi, Regional Manager Middle East, and Dr. Philippe from WFH, visited the Hemophilia Welfare Society's model Hemophilia Treatment Center (HTC) in Karachi. This center is emblematic of the unwavering dedication of the Hemophilia Bleeding Disorder Community.

During the visit, the WFH President and delegation interacted with patients and their families, inspecting treatment procedures and facilities. They lauded the center's services, noting its excellence surpassing that of many countries worldwide.
The lack of access to hemophilia treatment and awareness among patients and healthcare providers in Pakistan presents a significant challenge. To address this, the Hemophilia Welfare Society Karachi conducted a workshop on hemophilia management and care at its Institute of Transfusion Medicine and Blood Related Disease.
The workshop was graced by Mr. Cesar, President of the World Federation of Hemophilia, along with a delegation including Ms. Rana Safi, Regional Manager Middle East, and Dr. Philippe Andre. Dr. Darnaz Jamal, Secretary of SINDH Blood Transfusion Authority, was the guest of honor.
Attended by healthcare professionals, paramedics, and medical students, the workshop featured presentations by experts focusing on advanced treatment methods and hemophilia care.
Speakers, including President WFH Mr. Cesar, Ms. Rana Saifi, Dr. Philippe Andre, and Dr. Darnaz Jamal, stressed the importance of training healthcare providers in advanced treatment modalities.
Certificates were awarded to medical students at the workshop's conclusion, marking a significant step in enhancing hemophilia care awareness and expertise within the healthcare community in Pakistan.

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ONE-YEAR DIPLOMA COURSE:

THE FIRST INSTITUTE OF TRANSFUSION MEDICINE & BLOOD-RELATED DISEASES OF HEMOPHILIA WELFARE SOCIETY KARACHI WHERE 25 MEDICAL STUDENTS INCLUDING 5 HEMOPHILIA BLEEDING DISORDERS PATIENTS CAN GET 1YEAR DIPLOMA FROM A SINDH BOARD OF TECHNICAL EDUCATION ALONG WITH TRAINING TO MANAGE HEMOPHILIA AND RARE BLEEDING DISORDERS.

A ONE-DAY WORKSHOP ON HEMOPHILIA MANAGEMENT & CARE

The lack of access to hemophilia treatment and facilities, coupled with insufficient awareness among patients and healthcare providers, poses a significant challenge in Pakistan. There are limited opportunities for training in the management and care of hemophilia, exacerbating the issue.

To address this concern, a workshop on the management and care of hemophilia was conducted at the Institute of Transfusion Medicine and Blood Related Disease, established by the Hemophilia Welfare Society Karachi.

Mr. Cesar, the President of the World Federation of Hemophilia was the Chief Guest of the workshop and led a delegation that included the Regional Manager Middle East Ms. Rana Safi, and Dr. Philippe Andre. The guest of honor was Dr. Darnaz Jamal, Secretary of SINDH Blood Transfusion Authority.

The event was attended by Dr. Munira Borhany, Mr. Akhtar Hussain from the Sindh Board of Technical Education, healthcare professionals, paramedics, and a substantial number of medical students.

The workshop commenced with presentations by Dr. Sarfaraz Husain Jafri, Dr. Kaleem Khan, and Dr. Maliha, focusing on advanced treatment methods and the management and care of hemophilia.

Notable figures such as President WFH, Mr. Cesar, Regional Manager Middle East-WFH, Ms. Rana Saifi, Dr. Philippe Andre-, and Dr. Darnaz Jamal, along with other speakers, addressed the workshop. They emphasized the significance of training healthcare providers in advanced treatment modalities.

Certificates were distributed to medical students after the workshop, marking a step toward enhancing awareness and expertise in hemophilia care within the healthcare community in Pakistan.

Medical students receive certificates from President Mr. Cesar Alejandro Garrido D, Ms. Rana Saifi- Regional Manager Middle East, and Dr. Phillipe from the World Federation of Hemophilia at the One-day Workshop on Hemophilia Management held by the Hemophilia Welfare Society Karachi on Inauguration ceremony our training institute of Transfusion Medicine and Blood Related Disease.








PARTICIPATION IN WORKSHOP ON THE DEVELOPMENT OF NATIONAL BLOOD AND BLOOD PRODUCTS POLICY

The team from HWSK participated in the "Workshop on the Development of National Blood and Blood Products Policy 2022-27" held at Movenpick Hotel on February 2nd, 2022. This event, organized by the Islamabad Healthcare Regulatory Authority, aimed to establish the National Blood and Blood Products Policy for 2022-27, focusing on enhancing blood donation screening through NAT technology and regulating blood products.

As the designated focal authority, the Islamabad Healthcare Regulatory Authority is leading efforts to strengthen existing protocols and regulations for plasma fractionation. This workshop marked the third program of its kind conducted in each province. It is hoped that through these collaborative endeavors, a progressive national blood policy will be developed, benefiting the entire hemophilia community with positive outcomes.

INTERNATIONAL HEMOPHILIA ISTH TRAINING PROGRAM

We are delighted to announce that Dr. Muhammad Kaleem Khan has been chosen for training at the prestigious Royal College of London by the World Federation of Hemophilia (WFH) through the Ages Hemophilia Foundation - Pakistan and the Hemophilia Welfare Society Karachi. Dr. Khan also serves as a valued member of the medical advisory board of HWSK, where he has generously provided his expertise free of charge for many years.

Dr. Khan is renowned for his exceptional skills, competence, and extensive experience in treating patients on a daily basis. He is widely regarded as a top expert in his field. During his training tenure, Dr. Khan focused on oral care for hemophilic patients in Pakistan. Additionally, he conducted a retrospective study on dental management and compliance in accordance with WFH guidelines, presenting an insightful audit report on his findings.

Management of Severe Hemophilia A: Low-Dose Prophylaxis vs. On-Demand Treatment

Rabeea Munawar Ali [1], Madiha Abid [1], Sidra Zafar [1, 4], Muhammad Shujat Ali [2], Rukhshanda Nadeem [3], Raheel Ahmed [4], Munira Borhany [4]

1. Hematology, National Institute of Blood Disease & Bone Marrow Transplantation, Karachi, PAK 2. Research and Development, National Institute of Blood Disease & Bone Marrow Transplantation, Karachi, PAK 3. Physical Medicine and Rehabilitation, Hemophilia Welfare Society, Karachi, PAK 4. Hematology, Haemophilia Welfare Society, Karachi, PAK

Abstract

Introduction: Prophylactic clotting factor infusion regimens to prevent bleeding and joint deformity has become the standard of care in severe hemophilia A patients.

Aim: To assess low-dose factor prophylaxis in our population as an alternative approach to managing severe hemophilia A.

Methods: A prospective cohort study that included 68 hemophilia A patients divided into two groups, i.e., Prophylaxis and on-demand. The two groups were compared for annualized bleeding rate (ABR), hospitalization, units of factor VIII (FVIII) infused, or plasma products transfused, i.e., fresh frozen plasma (FFP) and cryoprecipitate (CP), and development of FVIII inhibitors.

Results: Of the 68 patients recruited in this study, 25 (36.7%) were in the prophylaxis group, and 43(63.3%) were in the on-demand group. The on-demand group presented a higher median-IQR ABR [8(20-3) vs. 5(10-1.5), p-value 0.024], several hospitalizations (39.7% vs. 0, p-value 0.001), and inhibitor development (9.3% vs. 0, p-value 0.289) compared to the prophylaxis group. The prophylaxis approach demonstrated a significant negative correlation of ABR with FVIII prophylaxis (r=-0484, p=value=0.014). Moreover, no hospitalizations or inhibitor development was observed in the prophylaxis group. The estimated annual consumption of FVIII was 328 IU/kg/ year in the on-demand group and 1662.6 IU/kg/year in the prophylaxis group. However, a highly significant difference in plasma product utilization was observed between the two groups, i.e., p-value <0.001 and 0.038 for FFP and CP, respectively.

Conclusion: Low-dose factor prophylaxis resulted in improved outcomes compared to on-demand treatment in terms of ABR, joint bleeding, hospitalization, and the development of inhibitors. This treatment approach should be adopted as an economically feasible alternative to high-dose Prophylaxis in resource-constrained countries.

Introduction

Hemophilia A is a rare bleeding disorder characterized by a deficiency of clotting factor VIII (FVIII) [1]. It is inherited as an X-linked recessive disorder. The severity of hemophilia A depends on plasma levels of factor VIII; <1% is severe, 1-5% is moderate, and 5-40% is mild hemophilia [2]. Severe hemophilia presents with recurrent spontaneous bleeding into joints and muscles, leading to hemophilic arthropathy [3]. Life-threatening bleeding, such as intracranial bleeding, is also observed among severe hemophiliacs [4].

Prophylactic clotting factor infusion regimens to prevent bleeding and joint deformity in severe h emophilia patients were first started in Sweden in 1958 [5] and have now become the standard of care in the developed world
[6]. The World Federation of Hemophilia (WFH) recommends high or intermediate-dose Prophylaxis started at an early age for all severe hemophilia patients [7]. However, resource-constrained countries face financial challenges in administering higher doses of clotting factor concentrates. Recent studies have also investigated low-dose factor prophylaxis as an alternative economically feasible approach [8,9]. The provision of clotting factor concentrates is a frequently faced obstacle in managing Hemophilia A patients in Pakistan [10].

In this study, we aim to assess the effectiveness of low-dose Prophylaxis against on-demand treatment, Pakistan's generally practiced treatment option [11]. The primary objective is to compare the annualized bleeding rate (ABR), hospitalization, and the amount of the factor used per year in patients with severe hemophilia A. Secondarily, we also aim to evaluate the frequency of development of factor inhibitors

between the two management approaches (i.e., low dose factor prophylaxis vs. On-demand treatment).

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"This article will be presented as a Poster at the International Society on Thrombosis and Haemostasis (ISTH) Congress from June 24-28, 2023".

Materials And Methods

This prospective cohort study was conducted at the National Institute of Blood Disease & Bone marrow transplantation (NIBD & BMT) and Hemophilia Welfare Society Karachi from February 2021 to July 2022. Patients of all ages diagnosed with Hemophilia A were included in the study. Non-consenting patients with missing data and those with other bleeding disorders or inhibitors to factor VIII at the time of enrollment were excluded from the analysis. This study was approved by the Institutional Review Board (IRB) of the National Institute of Blood Diseases (NIBD), Pakistan Ethics Committee, with NIBD/IRB-229/18-2021, and written informed consent was obtained from the study participants. The WFH-provided factor concentrates on low-dose Prophylaxis as humanitarian aid.

A purposive sampling technique was used to select patients. The demographic data, comorbid conditions, and intention of treatment were noted at baseline. Demographic and disease characteristics were considered to allocate the patients into two groups, i.e., Prophylaxis and On-demand group. Younger children were preferred in the prophylaxis group as they had fewer preexisting complications, lower body weights, and hence lower required doses of factor concentrates. The sample size was calculated using the WHO calculator on that the Confidence interval (1-α) was 95%, absolute precision required d=0.08, Anticipated population proportion P1=0.96, and P2=0.94 and n=57. Both groups were scheduled to receive secondary prophylaxis [7] to minimize bleeding complications. During the study duration, standard half-life recombinant factor concentrates (15 IU/kg twice weekly) were used for the prophylaxis group per WFH guidelines; however, active bleeding episodes were managed with factor concentrates as per recent WFH recommendations [7]. Plasma products, i.e., fresh frozen plasma (FFP) and cryoprecipitate (CP), were used for both Prophylaxis and on-demand groups if factor concentrates were unavailable. Participants in the 2 groups (Prophylaxis and on-demand treatment) were followed for at least one year to document the frequency, location, and nature of bleeding events, units of factors infused, type of blood products transfused, and development of inhibitors assessed on Activated partial thromboplastin time (APTT) based inhibitor screening [12].

Annualized bleeding rate, described as the number of bleeding events per annum, was calculated as the number of total bleeding events divided by the number of months in the reporting time window and multiplied by 12 [13].

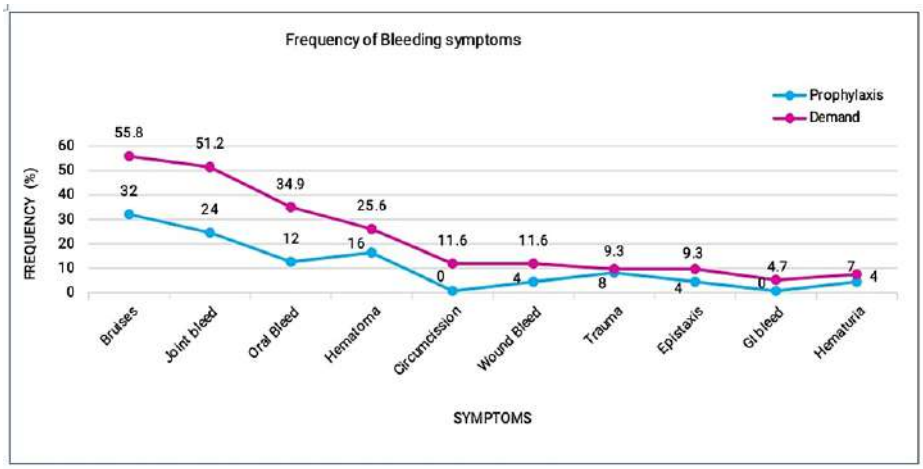
Statistical analysis

Data were analyzed using SPSS version 23. Non-parametric statistical analysis was applied based on normality; checked on Shapiro Wilk. Continuous quantitative variables were computed for descriptive analysis for estimating the median (IQR=Q3-Q1) age (year), weight (kg), and number of bleeding episodes (n); whereas a dichotomous, categorical variable was applied to quantify the frequency distribution in Prophylaxis, on-demand group, fresh frozen plasma, and cryoprecipitate in percent (%). Box plots and scattered plots were implemented to estimate the frequency of bleeding with factor VIII, FFP, and CP consumed in both groups, i.e., Prophylaxis and on-demand. However, inferential statistics were also applied, which includes the Mann-Whitney test to evaluate the association of Prophylaxis and on-demand group with age, weight, ABR, FVIII, FFP, and CP. However, bivariate correlation [Spearman correlation Rho (r)] was applied between annual bleeding rate with per unit utilization of FVIII, FFP, and CP in the Prophylaxis and on-demand group. A P-value of <0.05 was used as an indicator of statistical significance.

Results

A total of 68 patients were recruited in the study and segregated into two groups (prophylaxis 25 (36.7%) and on-demand 43 (63.2%)). Overall, the median (IQR) age was 7 (11.75-3.6) years, and the median annual bleeding rate (IQR) was 5 (15-2.25) for all participants. The on-demand group was found to have significantly higher values than the prophylaxis group. The most common bleeding symptoms were observed with bruises and joint bleeding, reported in 55.8% and 51.2% of patients in the on-demand group, which is higher than the prophylaxis group, i.e., 32% and 24%, as illustrated in Figure 1.

FIGURE 1: Frequency of bleeding symptoms in prophylaxis and on-demand group



A significantly higher median-IQR ABR of 8(20-3) was observed in the on-demand group compared to 5(10-
1.5) in the prophylaxis group (p-value 0.024), as depicted in Figure 2. The clinical characteristics by treatment group are presented in Table 1.

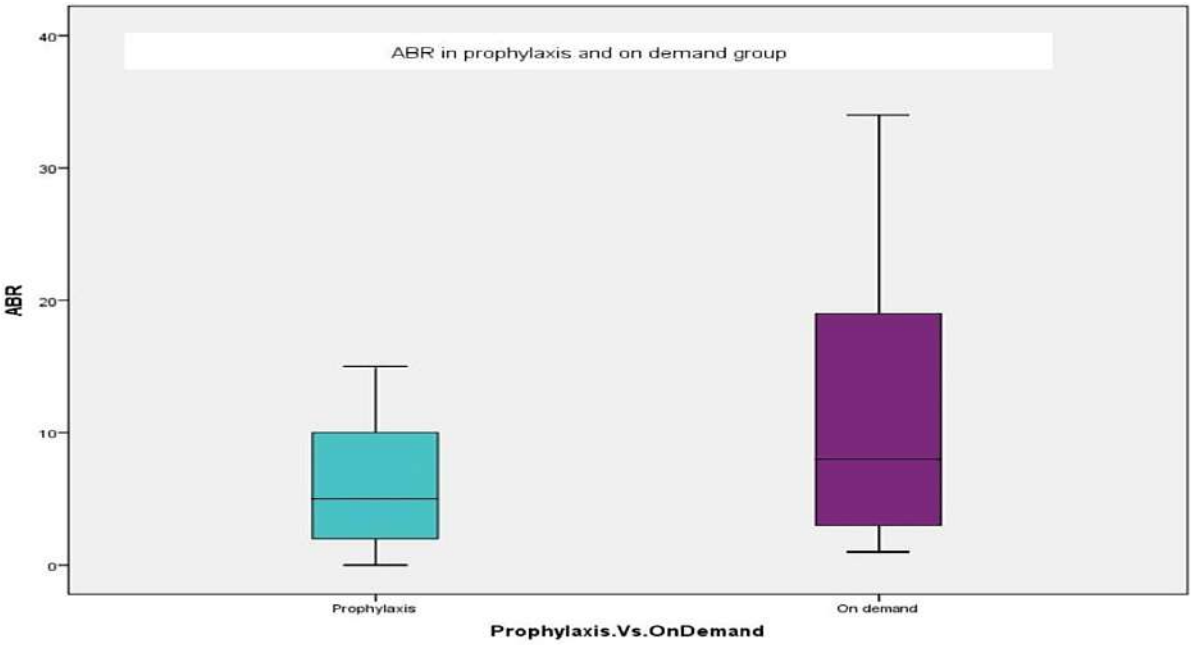


FIGURE 2: Annualized bleeding rate (ABR) in prophylaxis vs. on-demand group

Baseline Characteristics	Prophylaxis(n=25)	On-Demand(n=43)	P-value
	Median (IQR) and percent (%)	Median (IQR) and percent (%)	
Age (years)	5 (8-3.5)	10 (17-3.5)	0.028*
Weight (Kg)	14 (17.5-10)	30 (49-13)	0.001*
Annual bleeding rate (N)	5(10-1.5)	8(20-3)	0.024*
Factor VIII (IU)	23776 (23785-23673)	4156 (6985-2331)	0.001*
Hospitalization (%)	0	17(39.7)	0.001*

TABLE 1: Clinical profile of the patients on prophylaxis and on-demand therapy

Therefore, the median annual requirement of FVIII or plasma products in the two groups demonstrates a significant difference in the utilization of FVIII, FFP, and CP, respectively, thus indicating that more FVIII units were consumed in the prophylaxis group, whereas; plasma product transfusion was higher in the on-demand group. Out of 25 (36.7%) patients who were on Prophylaxis, 21 (30.9%) patients had minor bleeding episodes over a year requiring factor infusion or transfusion of FFP or CP. However, 17 (39.7%) of the patients were hospitalized in the on-demand group compared to none in the prophylaxis group with a p-value <0.001.

In the prophylaxis group, all patients were administered FVIII at regular intervals irrespective of bleeding symptoms; additionally, they were further given FVIII or FFP/CP transfusion in case of bleeding episodes. However, the frequency of FFP and CP usage was considerably lower in the prophylaxis group, i.e., 8% and 4%, compared to 72.1% and 23.3% in the on-demand group with p-value [<0.001 vs. 0.045], respectively.

The estimated consumption of factor VIII was 328.5 IU/kg/year in the on-demand group and 1662.6 IU/kg/year in the prophylaxis group. Moreover, 4 (9.3%) patients developed inhibitors to factor VIII in the on-demand group compared to none in the prophylaxis group (p-value=0.289), possibly due to the high need for transfusions in the former group.

The correlation of ABR with Prophylaxis showed a moderately negative but statistically significant correlation (r=-0.484; p-value=0.014). As a result, Prophylaxis has been associated with reduced bleeding episodes Figure 3.

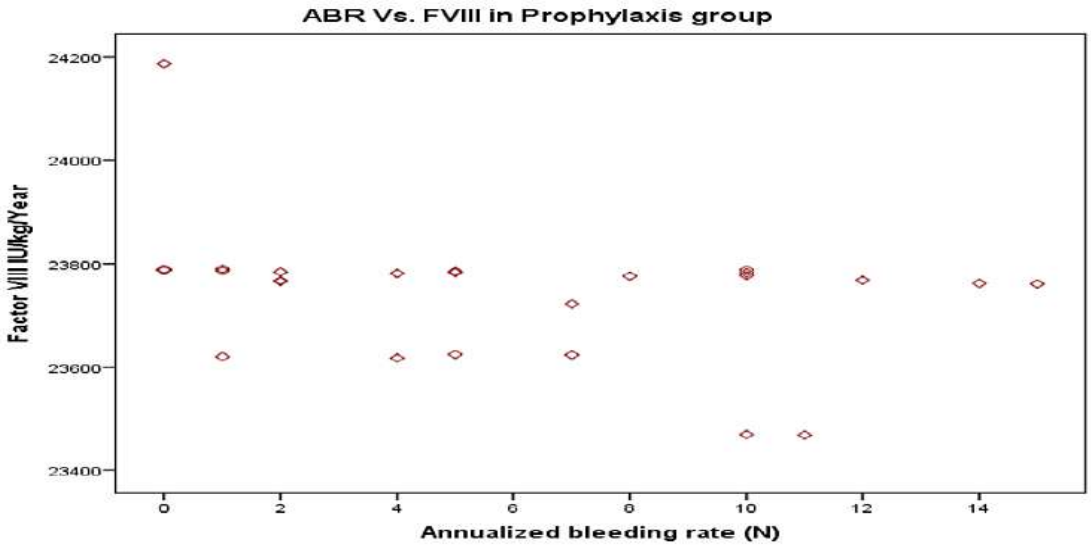


FIGURE 3: Annualized bleeding rates (ABR) with per unit infusion of Factor VIII (FVIII) in the prophylaxis group

Considering that a weak negative correlation (statistically insignificant) between ABR with FFP and CP was observed, i.e. (r=-0.049 and -0.071 with p-value=0.815 and 0.735), hence the relationship of FFP/CP and ABR was limited compared to the FVIII infusion in the prophylaxis group.

Likewise, a strong positive correlation was observed between ABR and on-demand treatment (r=0.718; p-value=0.001), indicating that increased bleeding episodes were associated with increased demand for rescue therapy (with factor VIII), as presented in Figure 4.

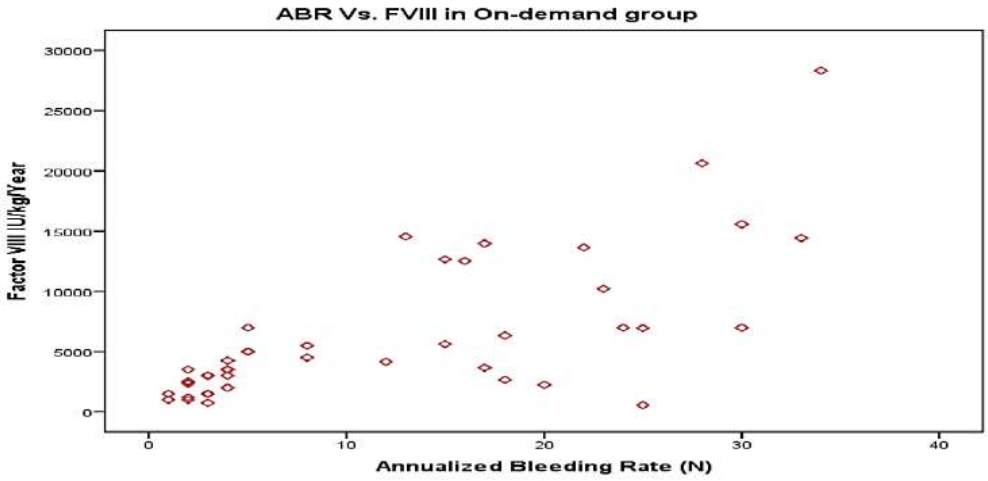


FIGURE 4: Annualized bleeding rates (ABR) with per unit infusion of Factor VIII (FVIII) in the on-demand patients

However, a moderately positive correlation was observed between ABR and FFP transfusion, i.e. (r=0.443, p-value=0.003), whereas a weak correlation was observed between ABR and CP, i.e. (r=0.235, p-value=0.129). Therefore, the FVIII and FFP need was significantly observed in the on-demand group.

Discussion

Hemophilia A has a prevalence of 17.1 cases per 100,000 males, with 6.0 cases per 100,000 males being severe Hemophilia A [14]. Despite being a rare disorder, hemophilia A poses a remarkable burden on health infrastructure [15] due to its debilitating nature [16], causing joint deformity [17] and even life-threatening bleeding [4].

Prophylaxis with clotting factor concentrates [6,7] to prevent serious bleeding complications has become the standard of care in Hemophilia A patients. Unfortunately, facilities for such initiatives are lacking in Pakistan. In this comparative analysis, we evaluated the efficacy of low-dose factor VIII prophylaxis as a potentially affordable option for these patients.

Our study demonstrated promising results for low-dose Prophylaxis, given the significantly decreased median ABR observed in this treatment approach compared to the on-demand group.

The percentage of patients experiencing joint bleeds has also reduced since the commencement of low-dose Prophylaxis, sparking the hope of improvement in joint function. Hence a follow-up of these patients may be able to demonstrate improvement in hemophilic arthropathy. Previous studies done to compare these two treatment approaches have shown results favoring low-dose Prophylaxis [18]. The previous study investigated 50 severe hemophilia A patients and reported a significant reduction in the total number of bleeding episodes, joint bleeds, and improvement in joint function (assessed by Hemophilia joint health score) in the low-dose prophylaxis group [9].

As developing countries often face financial constraints in providing factor concentrates for standard regimens, several investigators in these countries have used low-dose Prophylaxis as an alternative approach and displayed its benefits [19-21]. In addition to the advantages of reduced bleeding episodes and improved joint function, the study demonstrated reduced utilization of FVIII and, thus, the cost-effectiveness of low-dose Prophylaxis [8].

In our study, the number of hospitalizations was zero in the prophylaxis group, demonstrating that decreased severity of bleeds will eventually translate into an improved quality of life and decreased costs. In the prophylaxis group, a negative correlation was observed between ABR and FVIII, showing that

prophylactic administration of FVIII was significantly associated with a reduction in ABR. Despite these findings, our results were not optimal for the prophylaxis group as the ABR was still considerably high compared to the aim of zero bleeds on prophylactic treatment. Some researchers have also advocated Intermediate doses of FVIII [22] as it provides better bleeding outcomes than low-dose without substantial addition to the cost seen in high-dose Prophylaxis. Patient-tailored [23] and dose escalation regimens [24] explored in recent studies may also be used to overcome this shortcoming in our study population.

FVIII consumption in the prophylaxis group was more than on-demand group in contrast to findings of prior studies [8,21]. This contradiction might be explained by the increased use of plasma products in our on-demand cohort due to the unavailability of FVIII at the time of active bleeding. FFP and CP transfusion was significantly higher in on-demand therapy. This is a major drawback as managing active bleeding with plasma-derived products puts a patient at risk of transfusion-related reactions and infections (including Human immunodeficiency virus, Hepatitis B, and Hepatitis C) [25].

We observed the development of FVIII inhibitors in 4 on-demand patients compared to none in the prophylaxis group. Inhibitor development with on-demand therapy is a well-known phenomenon that can be reduced with the early commencement of Prophylaxis, as described by many researchers [26]. The RODIN study elaborated that inhibitor development occurs by exposure to high doses of FVIII in combination with tissue damage and inflammation at the time of active bleeding and can be overcome by prophylactic doses
[27].

The monoclonal antibody Emicizumab prophylactic administration [28] has emerged as an alternative to factor replacement in managing severe hemophilia A. However, this might not be possible with limited resources in the near future; hence developing countries such as Pakistan should focus on optimizing FVIII regimens tailored according to our patient population.

This is the first study to compare low-dose Prophylaxis with on-demand treatment in Pakistani Hemophilia patients. The major limitation of our study was limited access to FVIII, due to which we had fewer patients in the prophylaxis group and frequent use of plasma products in the on-demand group. Due to this, the annual consumption of FVIII could not be compared between the two groups. Apart from this, purposive sampling added selection bias, as the patients were enrolled at different ages, and their clinical characteristics were not comparable due to already existing arthropathy and increased transfusion requirement in some patients.

Conclusions

This study demonstrates improved outcomes with low-dose Prophylaxis vs. On-demand treatment in terms of ABR, the number of joint bleeds, the number of hospitalizations, and the development of inhibitors, but the benefits are not optimal. Although this approach offers a cost-effective alternative, more studies using patient-tailored or dose-escalation regimens are needed to establish better outcomes with economically feasible regimens.

Additional Information

Disclosures

Human subjects: Consent was obtained or waived by all participants in this study. Institutional Review Board (IRB) of the National Institute of Blood Diseases (NIBD), Pakistan Ethics Committee issued approval NIBD/IRB-229/18-2021. This study was approved by the Institutional Review Board (IRB) of the National Institute of Blood Diseases (NIBD), Pakistan Ethics Committee, with NIBD/IRB-229/18-2021, and written informed consent was obtained from the study participants. **Animal subjects:** All authors have confirmed that this study did not involve animal subjects or tissue. **Conflicts of interest:** In compliance with the ICMJE uniform disclosure form, all authors declare the following: **Payment/services info:** All authors have declared that no financial support was received from any organization for the submitted work. **Financial relationships:** All authors have declared that they have no financial relationships at present or within the previous three years with any organizations that might have an interest in the submitted work. **Other relationships:** All authors have declared that there are no other relationships or activities that could appear to have influenced the submitted work.

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Emicizumab Prophylaxis in Patients with Severe Hemophilia A: Insights from A Resource Limited Country

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Abstract

Emicizumab is a humanized, bispecific monoclonal antibody that connects active factor IX and X to replace the function of absent factor VIII, restoring hemostasis. It has a long half-life with a subcutaneous route of administration and high bioavailability. Here, we assessed the efficacy of Emicizumab prophylaxis in terms of efficiency, safety, and quality of life of severe hemophilia A (HA) patients with and without inhibitors before and after this treatment.
Methods: In this prospective study, severe HA patients were recruited from January 2022 to June 2023. Inhibitor positive and inhibitor negative patients with annual bleeding rate (ABR) 8 or greater and past histories of bleeding like intra-cranial, intra-abdominal, and pseudo-tumors were included. Emicizumab loading dose was 3 mg/kg in the first 4 weeks, and the maintenance dose was started at week 5 at 6 mg/kg/month. Patients' detailed bleeding history and demographics were recorded. The five-level EuroQol five-dimensional questionnaire (EQ-5D-5L) was used to evaluate patients' HRQoL. Furthermore, Hemophilia Joint Health Score (HJHS) and Functional Independence score in Hemophilia (FISH) were applied for the assessment of joints at different time points. Results were analyzed by SPSS version 21.

Results: A total of 36 HA male patients with the mean age of 19.7 ± 14.42 years were recruited in the study; among them, 19 patients were inhibitor positive, while 17 were negative. Patients clinically presented with bleeding symptoms which included: hemarthrosis 95%, GI bleeding 13.8%, and bruises and gums bleeding 13.8%. Significant reduction was observed in the bleeding episodes after the therapeutic intervention, and joints assessment and Euro-Quality-of-life Visual Analog Scale showed a signifi-cant improvement in health after treatment. Similarly, there was a remarkable reduction in bleeding episodes and improved quality of life among HA patients. The ABR decreased from 53.6% episodes per year prior to treatment to 2.4% during Emicizumab therapy. Prior to initiating Emicizumab therapy, participants exhibited an average FISH score of 16 and HJHS score of 10, indicating moderate limitations due to joint-related issues. After treatment, the mean FISH score improved to 9 and HJHS score to 4 reflecting a substantial enhancement in participants' ability to perform daily activities ($P < 0.057$).
Conclusion: Our results showed that HA patients on prophylactic treatment with Emicizumab were less restricted and had improved quality of life due to marked decrease in bleeding episodes which resulted in improved health and social lives. In addition, it was well tolerated, and no participant discontinued treatment because of adverse events.

Keywords

hemophilia A, bleeding, joint score, health-related quality of life, Hemophilia Joint Health Score, Functional Independence Score in Hemophilia, EQ-5D-5L

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determine the severity of HA patients.[2] Hemophilic arthropathy, a severe hemophilia complication, manifests as repeated spontaneous bleeding into muscles and joints.[3] In addition, severe hemophilia patients can potentially have life-threatening bleeding, such as intra-cranial hemorrhage, gastro intestinal bleed, joint bleeds, and malena.[4] The treatment of acute bleeding episodes is replacement of FVIII in these patients.[5] FVIII infusion requires regular dosage due to its short plasma half-life. HA patients who need FVIII replacement as prophylaxis get intravenous FVIII treatment at least two to three times per week. However, an important complication of FVIII treatment includes inhibitor development in which FVIII concentrates become ineffective in controlling bleeding symptoms and treatment becomes challenging in these patients requiring bypassing agents.[6]

Emicizumab (Hemlibra®) was designed to avoid the problems associated with repeated intravenous administration of FVIII and to provide a standardized treatment option for HA patients with or without inhibitors.[7] The drug Emicizumab is a humanized recombinant bispecific monoclonal antibody that restores missing activated FVIII function regardless of the factor VIII levels. Emicizumab promotes effective hemostasis in HA patients[8–10] and is considered to replace the hemostatic function of activated FVIII by combining activated factor IX and factor X (FX) to activate FX, facilitating the coagulation cascade and achieving hemostasis in HA patients.[11] The World Federation of Hemophilia (WFH) is providing humanitarian aid to underdeveloped countries to promote prophylaxis there. Benefits of prophylaxis are well known such as reduced pain and discomfort, reduced frequency of joint bleeding, and improved Qol but due to high cost and unavailability of factor concentrates, this is partially practiced developing countries. Fortunately, Pakistan is receiving factor concentrates and Emicizumab humanitarian aid for hemophilia patients through the Hemophilia Foundation of Pakistan which has registered hemophilia societies in different cities of the country. Hemophilia Welfare Society Karachi has registered congenital bleeding disorder patients (n = 1200) across the province of Sindh where patients receive treatment and rehabilitation through a multidisciplinary team. In the present study, we assessed the efficacy in terms of bleeding, safety, and quality of life of HA patients with and without inhibitors on Emicizumab prophylaxis (donated by the WFH through humanitarian aid to Pakistan) before and after this treatment.

Material and Methods

A prospective study was conducted at the Hemophilia Welfare Society Karachi, Pakistan (HWSK) from January 2022 to June 2023. This study was approved by the ethics committee of the HWSK/ 16-263/01-2022 in accordance with the declaration of Helsinki. Already diagnosed and registered severe HA male patients with inhibitors and without inhibitors were included with annual bleeding rate (ABR) 8 or greater and history of bleeding like intra-cranial (IC), intra-abdominal (GI), and pseudo-tumors were included in this study (the inclusion criteria set by WFH). The baseline clinical and laboratory data were collected. Emicizumab loading dose was 3 mg/kg in the first 4 weeks and the maintenance dose was started at week 5 at a dose of 6 mg/kg/month. The EuroQol five-dimensional questionnaire (EQ-5D-5L) included mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. These metrics were used to evaluate patients' HRQoL at baseline and then at 3 monthly intervals through this questionnaire. Furthermore, Hemophilia Joint Health Score (HJHS) and Functional Independence Score in Hemophilia (FISH) were applied for the assessment of joints at different time points (every 3 months).

Statistical Analysis

Statistical analysis was performed using SPSS-21 (Statistical Package for the Social Sciences). It was conducted to systematically examine and interpret the data collected in this study. By utilizing quantitative analysis, we aimed to provide objective and measurable insights into the effectiveness of the treatment. To determine the statistical significance of our findings, we established a value of significance, denoted as α (alpha) at 0.05. This signifies that we are willing to accept a 5% chance of making a type I error, which involves incorrectly rejecting the null hypothesis. A *P*-value less than α indicates that the observed effects are statistically significant, and we can confidently reject the null hypothesis in favor of the alternative hypothesis. *P*-values were used for hypothesis testing, suggesting a significant decrease in joint hemorrhages and an associated improvement in patients' mobility and joint function.

Employing a multi-faceted approach, we conducted qualitative and descriptive analyses to comprehensively assess the impact of the treatment on this cohort. Notably, our statistical analyses yielded significant results with a value of significance ($P < 0.05$). This statistical significance underscores the credibility of our findings, indicating that the observed effects are unlikely to have occurred by random chance. Furthermore, the implementation of a two-tailed ANOVA allowed us to distinguish meaningful differences before and after treatment, offering valuable insights into the treatment's effectiveness across multiple variables. In addition, a one-sample t-test specifically focused on the FISH scoring, providing a targeted evaluation of this specific aspect.

Results

Thirty-six male severe HA patients with mean ± SD 19.7 ± 14.42 years were enrolled. Among them, patients with inhibitor positive of more than 0.4 Bethesda unit / ml (BU) were 19 (52.77%), under 12 years were 6 (16.6%), and above 12 years were 13 (36.1%). Patients less than 12 years of age without inhibitor with ABR 8 or greater and past history of major bleeding (IC, GI, pseudo-tumors were 5 (13.8%). In addition, patients more than 12 years of age without inhibitors on a case-to-case basis and past histories of major bleeding were 12 (33.3%). Among them, history of consanguinity was present in 30 patients (83.3%) and family history of bleeding in 29

(80.5%). Details of demographic and clinical characteristics before and after the treatment of Emicizumab are shown in Table 1.

Upon initiating treatment with Emicizumab, a marked and statistically significant improvement was observed in patients' weight as average mean weight increased from 41 kg to 64.62 kg (n = 36), severity of major and minor bleedings decreased to <1%, and percentage of ABR reduced to 2.4%. When evaluating the HJHS and FISH scoring before and after treatment with Emicizumab, we evaluated the level of joint damage. Specific joint evaluations revealed that knee joints had the highest mean HJHS score (mean pre-treatment score = 10), followed by FISH scores by functional domain indicated that mobility had the lowest mean score (mean pre-treatment score = 16((16.1 ± 8.5)). Following the administration of Emicizumab, there was a notable reduction in the mean HJHS and FISH scores, and this decrease was statistically significant ($P < 0.057$) indicated an improvement in joint health as shown in Figure 1. Additionally included in the observed average EQ-5D-5L index score, mobility showed an impressive improvement of 63.3% (P=0.000) indicated a substantial increase in patients' ability to move and engage in physical activities. Self-care with an improvement rate of 66.6% (P=0.009) demonstrated enhanced independence in self-care tasks and regular activities, and a significant improvement rate of 70% (P=0.000) pointed to a significant positive shift in patients' ability to carry out their usual daily activities without pain/discomfort. Notably, the improvement in this domain was 52.6% (P=0.000) highlighting a reduction in pain and discomfort experienced by the patients. Similarly, anxiety/depression also improved 58.6% (P=0.000). Our results demonstrated a remarkable progress in overall joint health scores, showing a significant 45% (P=0.057) increase after every 3 months of therapy. This improvement indicated a significant reduction in joint hemorrhages and an associated increase in patients' joint mobility as demonstrated in Figures 2 and 3. Importantly, this outcome was statistically significant ($P < 0.05$), reinforcing the therapeutic benefits of Emicizumab on joints health. The positive impact on both Quality-Of-Life domains and joints health underscores the significance of this

Table 1. Demographic Characteristics of HA Patients Before and After Treatment of Emicizumab.

S No.	Demographic Characteristics	Before Treatment	After Treatment
	Age (years)	19.7 ± 14.42	20.7 ± 15.42
1.	Sex	Male	Male
2.	Total no. of hospitalization	N = 47	N = 2
3.	Absenteeism(days)	Mean = 69	Mean = 5
4.	Major bleeding	• Joint bleeding n = 9.27 (27%) • Intra-cranial bleeding n = 7.9(22.2%) • Knee bleed n = 6.9 (19.4%) • GI bleed n = 4.9 (13.8%) • Elbow bleed n = 4.9 (13.8%) • Hip joint bleed n = 3.99 (11.1%) • Rectal bleed n = 3.99 (11%) • Hematoma n = 1.98 (5.5%)	• Knee joint bleed after trauma n = 0.72 (2%)
5.	Minor bleeding	• Nasal bleeding n = 2.9(8.33%) • Gum bleeding n = 1.9 (5.55%) • Bruises n = 0.38 (1.06%)	• Bleeding after trauma n = 0.72 (2%) • Bruises n = 0.36 (1%)
6.	ABR	n = 110.6	n = 2.6
7.	Inhibitor	Positive (30.5%)	Positive (<1%)
8.	Prophylaxis patients to on demand therapy	(89%)	(10%)
9.	No of transfusions	• F-VIII conc. only 30 (83.3%) • FFP/CP 22(61.1%) • FFP/CP + FVIII conc. 21(58.3%)	• FFP/CP 31(86.1%) • FFP/CP + FVIII conc. 3(8.3%) • F-VIII conc. only 2(5.5%)
10.	Adverse reactions to therapy	• Allergic reactions n = 0.97 (2.7%) • Urticaria n = 0.79 (2.2%)	• Weight gain n = 35.28 (98%) • Sleep disturbance n = 4.96(13.8%) • Stomachache n = 0.97 (2.7%) • Inflammation at the site of injection n = 0.97 (2.7%)
11.	Any surgery performed	• Tibial fracture n = 0.97(2.7%)	• Knee surgery n = 1.9 (5.5%) • Endoscopy n = 1.9 (5.5%) • Circumcision n = 0.97 (2.7%) • Tooth extraction n = 0.79 (2.2%) • Tibia plating + screw n = 0.79 (2.2%) • Endoscopy + colonoscopy n = 0.79 (2.2%)
12.	FISH scoring	Average scoring; (16)	Average scoring; (9) *P*-value; 0.057
13.	HJHS	Average scoring;(10)	Average scoring;(4)

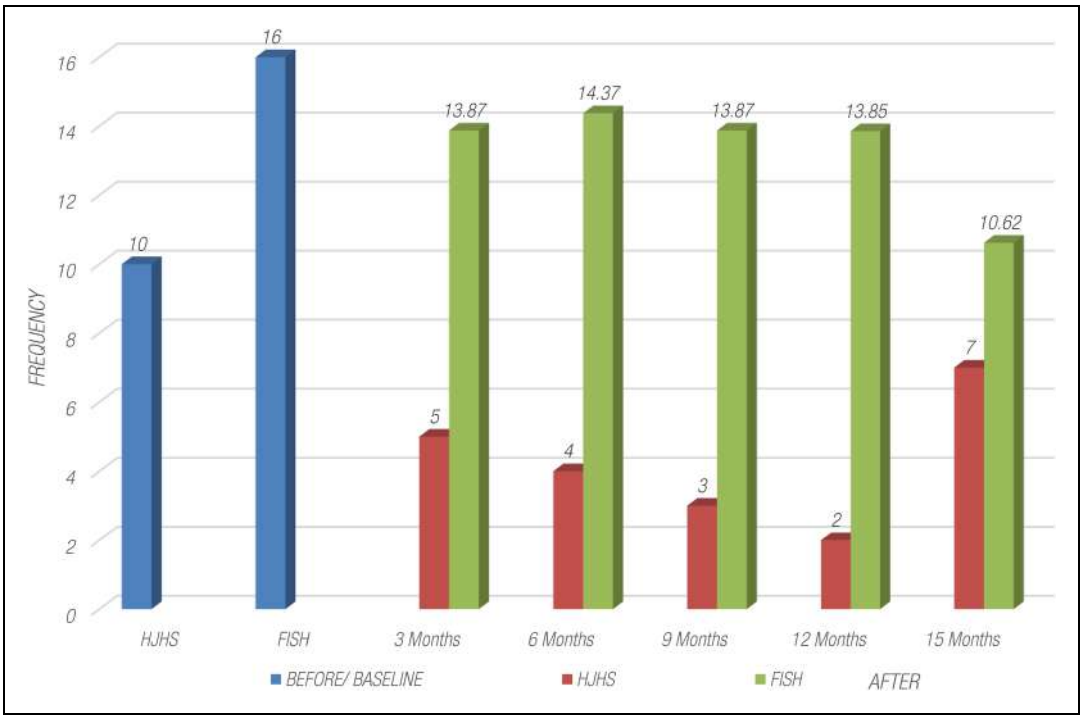

Figure 1. Evaluation of HJHS and FISH scoring before and after treatment of Emicizumab. FISH, Functional Independence score in Hemophilia, HJHS, Hemophilia Joint Health Score.

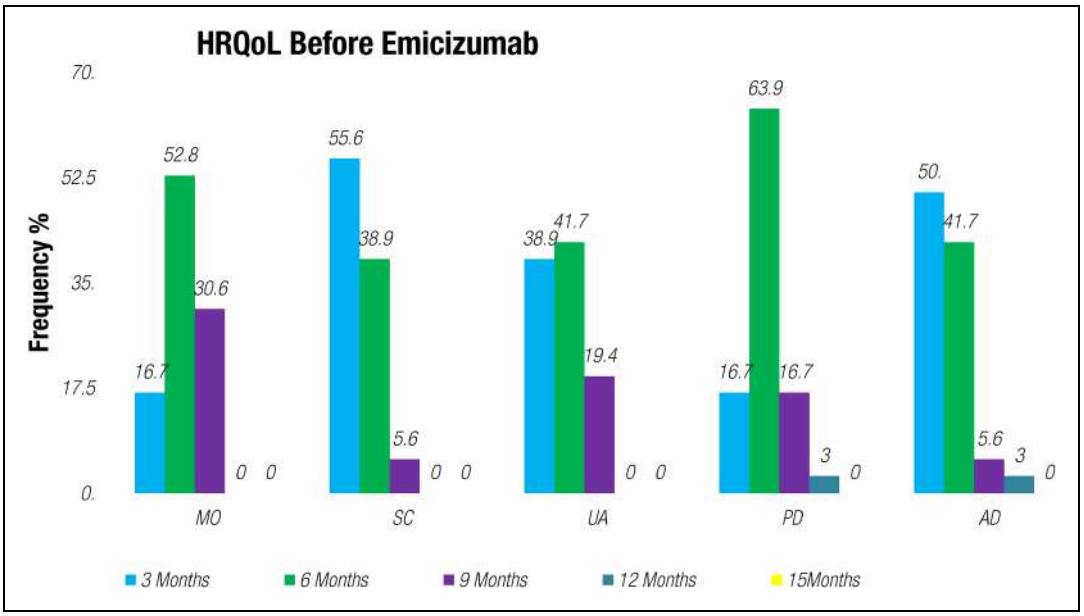

Figure 2. HRQoL Pre-treatment with Emicizumab. MO: mobility SC: self-care UA: usual activities PD: pain/discomfort AD: anxiety/depression.

therapeutic intervention for enhancing the well-being and clinical outcomes of patients with HA.

Discussion

This study was conducted on severe HA patients receiving Emicizumab prophylaxis highlighting the efficacy of its treatment in terms of bleeding, safety, and quality of life with and without inhibitors and its analysis shows that it was well tolerated with improvement in the joint scores in different intervals of time. Moreover, efficacy data were consistent among those with or without FVIII inhibitors and a significant reduction in rate of bleeding was observed after the treatment with ABR (2.4%) highlighting the safety and better clinical outcomes with the administration of Emicizumab in HA patients which was consistent with the findings of previously reported

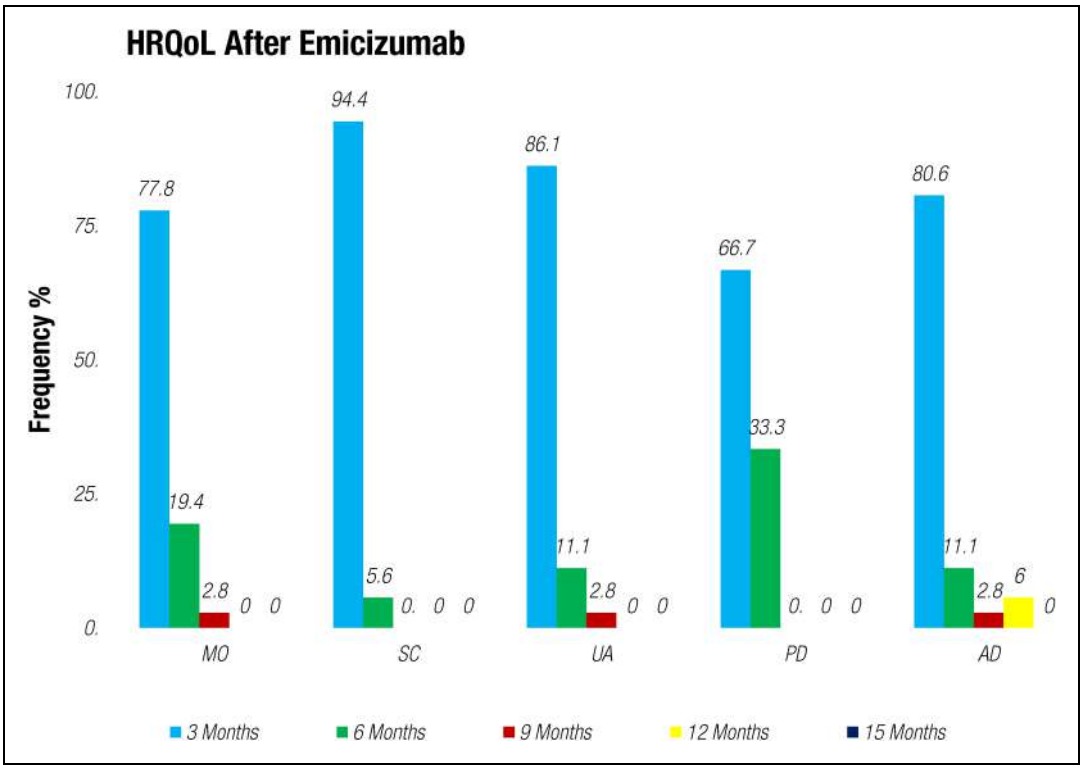

Figure 3. HRQoL Post-treatment with Emicizumab. MO: mobility SC: self-care UA: usual activities PD: pain/discomfort AD: anxiety/depression.

studies.[12–15] In addition, further benefits of Emicizumab were evaluated and significantly reduced rate of bleeding was observed in patients with major and minor bleeding episodes. More than 90% of the patients receiving prophylaxis experienced reduced joint bleed (2.4%) after receiving Emicizumab suggesting its long-term efficacy which was also observed by the HAVEN program.[16]

The HRQoL is a five-level questionnaire that assesses on mobility, self-care, usual activities, pain/discomfort, and anxiety/depression, and there was a notable reduction in the mean HJHS and FISH scores, and this decrease was statistically significant ($P < 0.057$), indicating an improvement in joint health. (Figure 1) The significant improvement in this domain was 52.6% (P=0.000) highlighting a reduction in pain and discomfort experienced by the patients. Similarly, anxiety/depression improved 58.6% (P=0.000) which was also observed in previous studies.[17–19] Additionally, the HJHS and FISH scores were also evaluated for the assessment of joint damage and significant reduced scores were observed after the treatment of Emicizumab ($P < 0.057$) indicating better response of Emicizumab for the joint damage as the improvement was also observed in young hemophilic patients in Haven 3 study without the factor VIII inhibitors.[20]

The baseline parameters like age and occurrence of target joint are important predictors for the improvement of HRQoL, HJHS, and FISH scores that emphasizes for further multi-center studies with large number of sample size from different countries. This was the first single-center prospective study conducted to assess the efficacy in terms of bleeding, safety, and quality of life of HA patients with and without inhibitors on Emicizumab prophylaxis before and after treatment. This emphasizes on the use on prophylaxis especially in the severe hemophilic patients for better outcomes in children and adolescences to promote zero bleeds in these patients.

Conclusion

Significant and important improvements were observed in terms of bleeding, HRQoL, HJHS, and FISH scores in severe HA patients treated with Emicizumab prophylaxis. These strong efficacy and safety data, together with a clinically significant improvement suggest that Emicizumab improves patient care by reducing the burden of treatment, which in turn allows effective adherence to prophylaxis and reduces secondary complications in these patients. In conclusion, this study's findings show a lot of possibilities for solving serious issues in terms of joint bleeding and deformities, QoL and cost-effective therapy as compared to on-demand treatment. By recognizing the revolutionary potential of this research, we open the door for creative solutions that will enable developing countries to rise above hardship and create more promising and resilient futures.

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Authors Contributions

M. Borhany conceived the idea of this study and wrote the manuscript. A. Arshad helped with writing. Rakshanda did data collection and physiotherapy assessment. H. Qureshi did data analysis. R. Ahmed helped in patient assessment and counseling along with M. Borhany. All authors have read and approved the manuscript.

Consent

Written informed consent was obtained from the participants of the study for their anonymized information to be published.

Data Availability

The Dataset used and/or analyzed during the current study is available from the corresponding author on reasonable request.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Ethical Approval

A prospective study was conducted at the Hemophilia Welfare Society Karachi, Pakistan, (HWSK) from January 2022 to June 2023.This study was approved by the ethics committee of the HWSK/ 16-263/ 01-2022 in accordance with the declaration of Helsinki. Confidentiality of participants and privacy was maintained during the data collection process.

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Future Directions

Conducting multi-center studies with a greater number of patients with hemophilia may help to understand the effects Emicizumab prophylaxis on the outcome, especially in our population.

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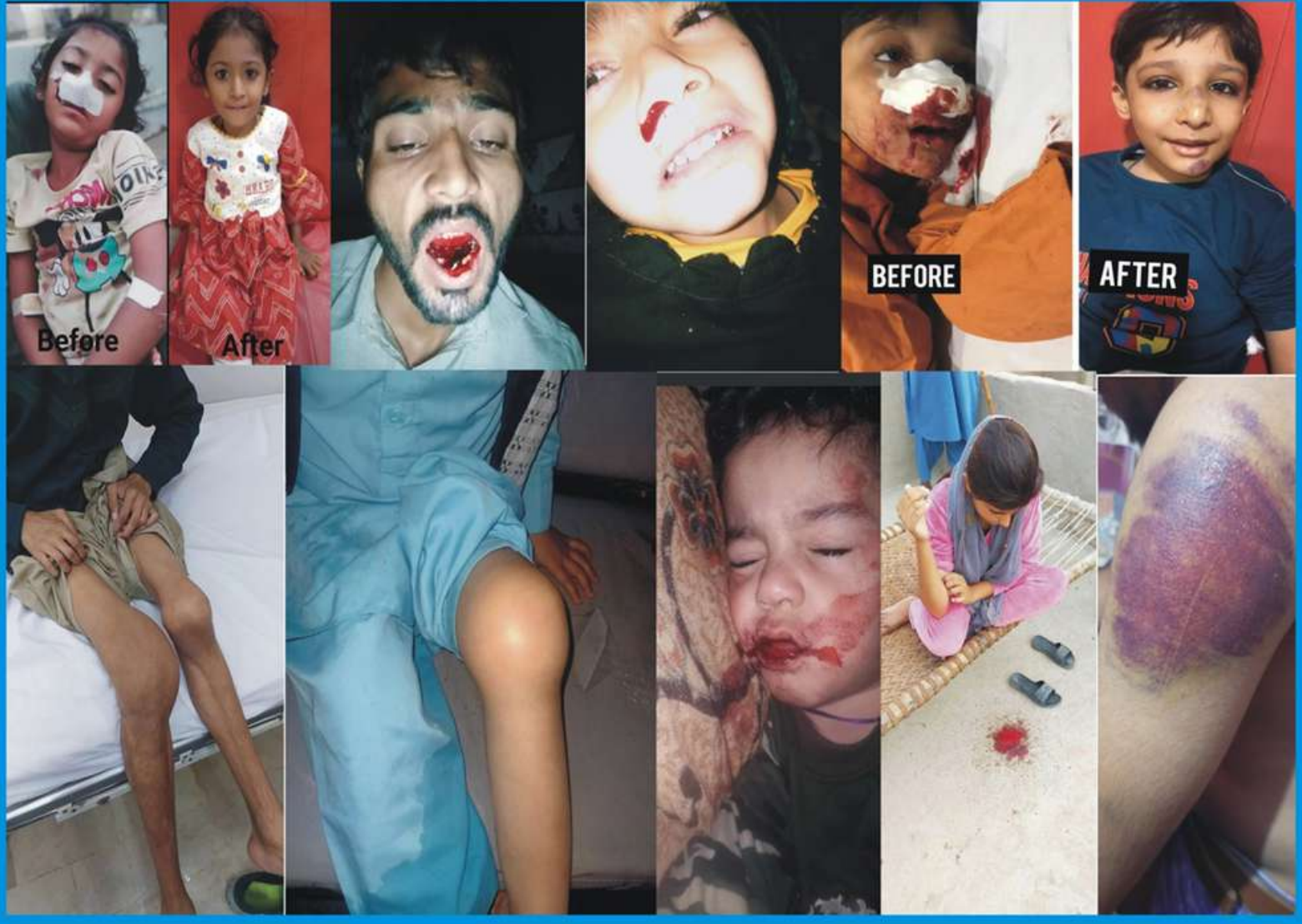

Hemophilia At A Glance

HWSK EXPANDED AS THE 1ST MODEL HEMOPHILIA TREATMENT CENTER IN SINDH

In Karachi, Sindh Social Welfare Minister Muhammad Sajid Jokhio inaugurated Pakistan's first Model Hemophilia Treatment Center, led by the Hemophilia Welfare Society Karachi (HWSK) in Nazimabad. This cutting-edge facility, designed to provide comprehensive care for hemophilia patients, is the nation's inaugural endeavor of its kind. Notable figures including Raheel Ahmed (founder and CEO) and Dr. Sarfaraz Jafri attended the ceremony, highlighting its significance.

During the inauguration, Minister Jokhio officially opened the center, interacting with patients and their families to grasp their challenges firsthand. Raheel Ahmed emphasized the center's 15-bed capacity and advanced treatment options, acknowledging the financial support from WFH and the Sindh government's contribution of 24 million rupees. He stressed the ongoing need for increased funding to address treatment needs adequately.

Mr Raheel Ahmed also outlined HWSK's collaborative vision with the Sindh government to establish disease prevention initiatives at the district level. With 5200 hemophilia patients in Sindh, only 1100 registered, Ahmed emphasized the urgency of addressing the scarcity of essential medication.

Minister Jokhio reaffirmed the government's support, pledging to secure a more substantial budget and allocate dedicated space for the Hemophilia Center. This center represents a pivotal milestone in Pakistan's healthcare, symbolizing a joint effort to improve hemophilia patients' quality of life.







LAUNCHING OF THE FIRST HEMOPHILIA GUIDELINES WORKSHOP

Pakistan, a developing country, faces a significant challenge with low awareness about hemophilia and lacks a structured treatment framework at the public sector level. Unfortunately, advanced treatment products essential for managing hemophilia according to global standards are also unavailable. Establishing Hemophilia National Treatment Guidelines is crucial to raise awareness among the medical community and ensure breakthrough management and care for bleeding disorders nationwide. To address this issue, the Hemophilia Welfare Society Karachi (HWSK) organized an event sponsored by the World Federation of Hemophilia (WFH) – Path to Access to Care and Treatment (PACT Program) in collaboration with the Hemophilia Foundation Pakistan (HFP) at Regent Plaza Hotel & Convention Centre Karachi on January 3, 2023. This event aimed to inform medical personnel about the current challenges in hemophilia treatment and diagnosis within the country. Notably, it marked the first instance in Pakistan where representatives from hemophilia societies, government officials, and doctors from both public and private sectors jointly briefed the press, shedding light on the debilitating situation of hemophilia in the country.

LAUNCHING OF THE FIRST HEMOPHILIA GUIDELINES WORKSHOP
















PAKISTAN CENTRE FOR PHILANTHROPY (PCP) NPO CERTIFICATION AWARD FOR HEMOPHILIA WELFARE SOCIETY KARACHI

The Hemophilia Welfare Society Karachi has been awarded the Pakistan Centre for Philanthropy (PCP) NPO Certification for its outstanding commitment to excellence and leadership. This recognition reflects adherence to evaluation standards set forth by the Federal Board of Revenue (FBR).

MEETING WITH THE HONORABLE MINISTER OF SOCIAL WELFARE DEVELOPMENT (SWD) GOVT. OF SINDH :

The team from the Hemophilia Welfare Society recently met with the Honorable Minister of Social Welfare Development (SWD), Mr. Mohammad Sajid Jokhio, to discuss extending the services and facilities of HWSK across the entire Sindh province with the support of SWD.

HONOURABLE MINISTER FOR SOCIAL WELFARE DEPARTMENT GOVT.OF SINDH VISITED HWSK HTC

Provincial Social Welfare Minister Muhammad Sajid Jokhio inaugurated our 1st Model Hemophilia Treatment Center (HTC) in Karachi, distributed educational and financial assistance cheques donated by Save One Life (SOL), and expressed government support for hemophilia patients in Sindh. Joined by HWSK representatives, Minister Jokhio acknowledged the center's commendable care for patients and pledged ongoing assistance for bleeding disorder services province-wide.

Raheel Ahmed, Founder & CEO informed the minister that the Hemophilia Center, currently treating 1050 patients, is set to expand from 10 to 50 beds with the shift to a new location. He highlighted the urgent requirement of Rs.20 million for equipment, machinery, and clinical resources to facilitate this expansion.

MINISTRY OF HEALTH, GOVT OF SINDH IS CONVINCED AND WILLING TO WORK TOGETHER WITH HWSK

The Government of Sindh's Ministry of Health has reaffirmed its commitment to collaborate with HWSK, pledging to enhance facilities, expand services, and provide diagnostic assistance at the district and division levels. This commitment was solidified during a meeting chaired by Minister of Health Dr. Azra Pechuho, alongside Secretory Health and Director of Sindh Blood Transfusion Authority, Dr. Dur-r-Naz Jamal, at EOC.

Following this meeting, a directive was issued to all Medical Superintendents and Civil Surgeons to nominate relevant health professionals from tertiary care hospitals across Sindh for advanced training in hemophilia care. This training aims to ensure compliance with WHF Treatment Guidelines/Protocols for effective management of hemophilia patients province-wide.

In a groundbreaking development, the Government of Sindh's Health Department has allocated funds in its budget for Hemlibra prophylaxis treatment. This initiative marks a significant step forward, granting six children affected by hemophilia A access to prophylaxis treatment for the first time in Pakistan.

PRODUCTIVE HEMOPHILIA ADVOCACY PLASMA FRACTIONATION

A recent meeting chaired by Chief Minister Syed Murad Ali Shah at CM House Karachi focused on the health sector, attended by Health Minister Dr. Azra Fazal Pechuho, Parliamentary Secretary Qasim Soomro, Health Secretary Zulfiqar Shah, and other officials including Secretary SBTA Dr. Dur-e-Naz Jamal and Raheel Ahmed from Hemophilia Welfare Society Karachi.

Dr. Dur-e-Naz Jamal highlighted the rising demand for plasma-derived products, stressing the importance of stringent regulation and monitoring during plasma fractionation due to safety concerns and financial constraints.

Chief Minister Syed Murad Ali Shah expressed optimism and directed further action on the project. He commended the dedication of Dr. Dur-e-Naz Jamal and Health Minister Dr. Azra Fazal Pechuho.

Raheel Ahmed discussed the challenges in hemophilia treatment, highlighting the scarcity and costliness of Clotting Factor Concentrates (CFCs) in Pakistan. He emphasized the potential benefits of plasma fractionation initiated by the Sindh Government, foreseeing improvements in the lives of individuals with hemophilia and other bleeding disorders.

SIGNED MOU WITH LIAQUAT UNIVERSITY OF MEDICAL & HEALTH SCIENCES FOR THE BETTERMENT OF HEMOPHILIA & OTHER BLEEDING DISORDERS

The Hemophilia Welfare Society Karachi (HWSK) and Liaquat University of Medical and Health Sciences (LUMHS) in Jamshoro have signed a significant Memorandum of Understanding (MoU) to enhance hemophilia and bleeding disorder care at Civil Hospital Hyderabad.

This landmark agreement will provide closer diagnosis and treatment services to hemophilia patients in Hyderabad and nearby areas, reducing the need for travel to Karachi. Led by Founder and CEO Raheel Ahmed, a delegation from HWSK, including key members such as Fakhre Alam Zaidi and M. Shahid Dawood, visited Hyderabad to finalize the agreement with LUMHS. The MoU, signed by LUMHS Vice Chancellor Prof. Ikram Din Ujjan and Raheel Ahmed, marks a major step forward in improving care for hemophilia patients.

Prof. Ujjan expressed his support for the agreement, recognizing its importance. Raheel Ahmed highlighted that the MoU includes providing free world-class treatment to 285 registered patients, backed by support from the World Federation of Hemophilia humanitarian aid program. Moreover, HWSK will assist in training the university's doctors to enhance their expertise in hemophilia care.

During their visit to Civil Hospital Jamshoro, the delegation received a warm welcome and toured various hospital departments, including Diagnostic and Research Laboratory, Hematology, Molecular Biology and Virology, Cytogenetics, Children's Emergency, Thalassemia, and Hemophilia Wards.

HEMOPHILIA ADVOCACY AT THE GOVERNMENT LEVEL

Meeting with Imdad Ali Chana the Director of Social Welfare Karachi along with Mr. Shahid Saleem Ex-Additional Director of Sindh Government.

SATELLITE HEMOPHILIA TREATMENT CENTER

Collaboration to establish a Hemophilia Treatment Center (HTC) at Super Highway Dumba Goth Hospital, Sindh Government, was discussed with Mr. Muhammad Sajid Jokhio, Minister of Social Welfare. The aim is to set up a satellite Hemophilia Treatment Center (SHTC) at Super Highway to serve patients from remote areas in Sindh currently traveling to our Karachi HTC.

Our goal is to establish hemophilia treatment centers in every district-level government hospital, ensuring patients receive treatment and awareness locally.

We thank Honorable Minister Muhammad Sajid Jokhio for his efforts in establishing the HTC at Super Highway Dumba Goth Hospital. Special thanks to the management of Dunba Goth Hospital, Dr. Jameel Mughal, DHO district Malir, MS Dr. Aftab Jokhio, for their support and assurance of full hemophilia care. Appreciation also goes to Chairman Darsana Chanu Nabi Bakhsh Palari, Mujahid Jokhio, Mr. Zohaib Shaikh of PPHI, and others for their support.

DOCTOR OF PHYSIOTHERAPY (DPT) INTERNSHIP CERTIFICATE DISTRIBUTION

Dr. Saba Jamal from Indus Hospital & Health Network visited our Hemophilia Treatment Center (HTC), marking a significant collaboration with HWSK.

During her visit, Dr. Jamal discussed strategies for expanding healthcare access in Sindh Province, including the establishment of Satellite Treatment Centers, and explored innovative treatments and research advancements.

Additionally, Dr. Jamal led a certificate distribution ceremony for our second batch of DPT interns from MC College of Medical & Allied Health Sciences, highlighting our commitment to nurturing healthcare professionals and community support.

Such partnerships are crucial for providing comprehensive care and a brighter future for individuals with hemophilia. Together, we can make a meaningful impact on their lives.

MEETING WITH CARE TAKER HEALTH MINISTER & DR FAIZ ALI MANGI

Successful meeting of representatives of Hemophilia Welfare Society Karachi with Caretaker Health Minister Sindh Government Dr. Saad Khalid Niaz and Chief Technical offer Dr. Faiz Ali Mangi to make possible and accessible the provision of hemophilia treatment and facilities in Sindh Province.

MEETING WITH DEPUTY MAYOR KARACHI METROPOLITAN CORPORATION

Hemophilia Welfare Society Karachi representatives Met with Salman Abdullah Murad Dupty Mayor of Karachi Sindh Government with Azmatullah Loond

Duty Mayor Mr. Salman Abdullah assured all possible cooperation to ensure the provision of hemophilia treatment and facilities at the district level.

Karachi Metropolitan Corporation

SEMINAR STAKEHOLDER'S SOLIDARITY WITH HEMOPHILIA AND BLEEDING DISORDERS IN KARACHI.

The Hemophilia Welfare Society Karachi hosted the Stakeholder's Solidarity Seminar on Hemophilia and Bleeding Disorders in Karachi. The event was graced by the presence of Mr. Cesar Garrido, the President of the World Federation of Hemophilia, as the chief guest. Notable attendees included Rana Saifi, Dr. Phillipe from WFH, and Dr. Faiz Ali Mangi from the Health Department Sindh Government. The seminar drew a diverse audience, comprising government officials, medical professionals, and representatives from nonprofit organizations, pharmaceutical companies, and members of the media.

CELEBRATE WORLD BLOOD DONOR DAY

The Hemophilia Welfare Society Karachi celebrated World Blood Donor Day 2023 with deep gratitude at our center. Collaborating with patients and families affected by bleeding disorders, we organized informative sessions highlighting the vital significance of blood donation. These sessions aimed to raise awareness, express heartfelt appreciation to donors, and emphasize their pivotal role in saving lives. Together, we are dedicated to promoting the importance of giving the precious gift of life.

PRINT PUBLICATIONS & ELECTRONIC MEDIA

HEMOPHILIA & THE IMPACTS OF THE EVER-INCREASING INFLATION IN PAKISTAN

Raheel Ahmed, Founder & CEO, advocated for allocating 10% of Privileges and Protocols funds by both federal and provincial governments for bleeding disorders like hemophilia in Pakistan. He highlighted the urgency of this measure amidst current inflationary pressures, emphasizing its potential to save lives. Ahmed also called upon other provinces to emulate Sindh's prompt actions to enhance hemophilia care.

As inflation escalates in Pakistan, individuals with hemophilia encounter formidable obstacles in accessing vital daily treatment. Their struggle for survival intensifies compared to healthy individuals, exacerbating the challenges faced by charitable organizations striving to support them.

HEMOPHILIA AWARENESS

Meet Dr. Munira Borhany (Consultant Hematologist/Oncologist & Bone Marrow Transplant Physician Medical Director Hemophilia Welfare Society Karachi attended radio FM 105 program Health for Everyone.

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Founder | Abul Hasan Usmani | Editor-in-Chief | Aneel Ahmed Usmani

WFH team visits Hemophilia Centre Nazimabad

By Staff Reporter

KARACHI: World Federation of Hemophilia (WFH) President Cesar Guerredo with his international delegation visited Hemophilia Model Treatment Centre in Nazimabad by Hemophilia Welfare Society. President WFH was accompanied by Regional Manager (Middle East) Rana Saifi and Philippe Andre de Morlos. He was received by founder CEO Hemophilia Welfare Society Raheel Ahmed and his team. Head of Sindh Blood Transfusion Authority Dr Durenaz Jamal was also present.

Cesar met patients and their families at treatment centre and inquired about their well-being. He asked about problems faced by patients during treatment. Cesar Guerredo along with Raheel Ahmed and others inaugurated training institute of society. Talking to media Cesar said that he was very satisfied to see work of Haemophilia Welfare Society and federation is working together with Haemophilia Welfare Society.

He said that under Hemophilia Welfare Society Karachi, good work is being done here in comparison with many other countries. With help of Federation, Pakistani hemophilia patients are getting world-class treatment and it will be continued, he assured. Cesar Guerredo and other members appreciated efficiency and treatment facilities of centre. Raheel Ahmed said that Hemophilia Welfare Society is grateful for support of World Federation. He said that hemophilia patients are suffering from severe problems in Pakistan. Hemophilia treatment facilities should be provided at government level.

He demanded that hemophilia departments should be established in divisional and district hospitals of Sindh. He requested Drug Regulatory Authority Pakistan to allow sale of hemophilia drugs in medical stores. Dr. Durenaz Jamal said that government of Sindh is first government in region which has started working on hemophilia. Abbas Ali Zaidi-National Member Organisation and President Hemophilia Foundation, Anisur Rehman-President HWSK, Fakhar Alam Zaidi-founder member and finance secretary, Rana Asghar Ali, Shahid Dawood-founder General Secretary HWS and Arif were present.

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Treatment of haemophilia at govt hospitals urged

OUR CORRESPONDENT
KARACHI

Sindh Blood Transfusion Authority (SBTA) head Dr Durenaz Jamal has said the provincial government was striving to support haemophilia patients.

"Sindh takes the lead when it comes to treating the haemophilia disease," she said at the inauguration ceremony of a training institute at the Nazimabad's Model Treatment Centre.

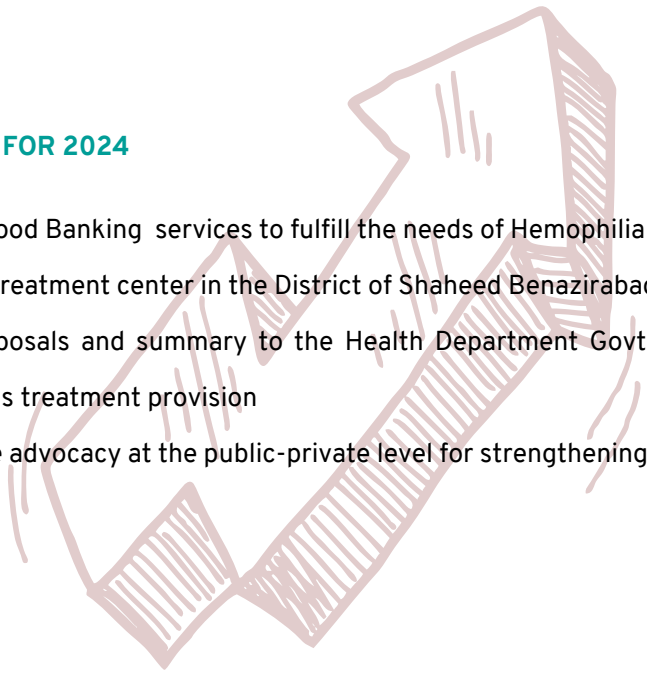
World Federation of Haemophilia (WFH) President Cesar Guerredo and his delegation, including Regional Manager (Middle East) Rana Saifi and Philippe Andre de Morlos, were the chief guests. Haemophilia Welfare Society CEO Raheel Ahmed was also present on the occasion.

Dr Jamal said the government had provided funds to some patients, and added it would try to increase the funding so that more patients could avail the facility. She called for creating awareness about diseases like haemophilia.

Haemophilia is usually an inherited bleeding disorder in which the blood does not clot properly.

This can lead to spontaneous bleeding as well as bleeding from injuries or during the surgery. Blood contains many proteins called clotting factors that can help to stop bleeding.

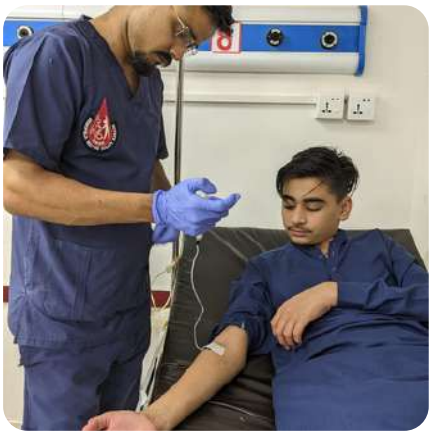
She welcomed the delegation of the World Federation of Haemophilia in Sindh.



STRATEGY PLAN FOR 2024

- To establish Blood Banking services to fulfill the needs of Hemophilia patients
- To establish a treatment center in the District of Shaheed Benazirabad
- To submit proposals and summary to the Health Department Govt. of Sindh 250 children of Hemophilia kids treatment provision
- To enhance the advocacy at the public-private level for strengthening and sustaining our services.

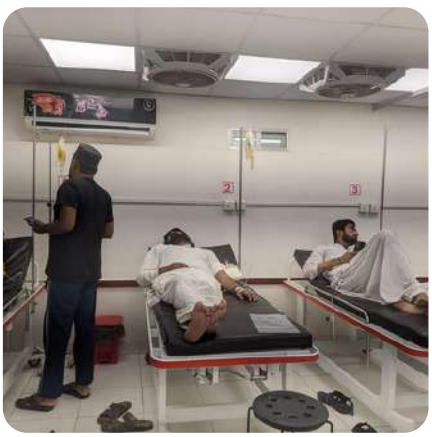












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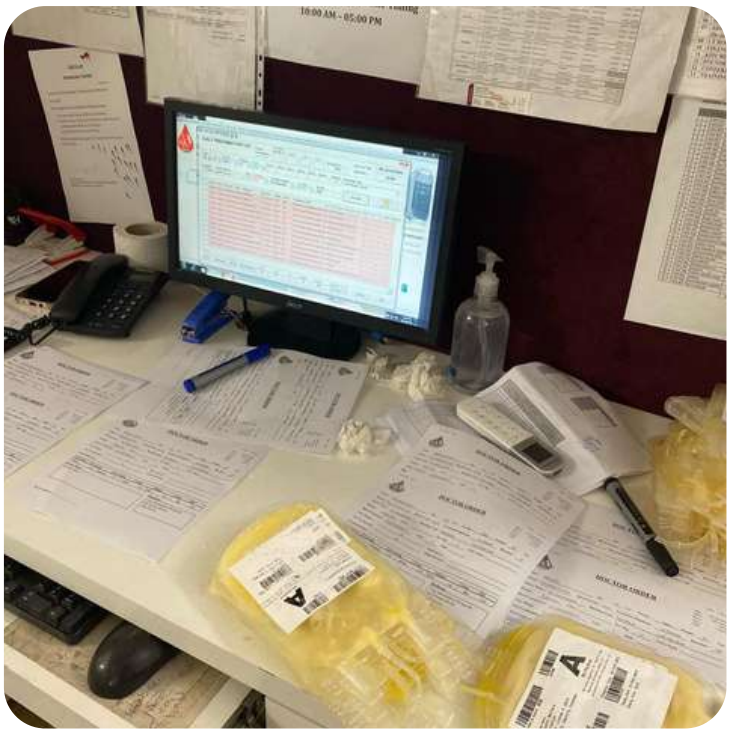
Medicines of Hemophilia



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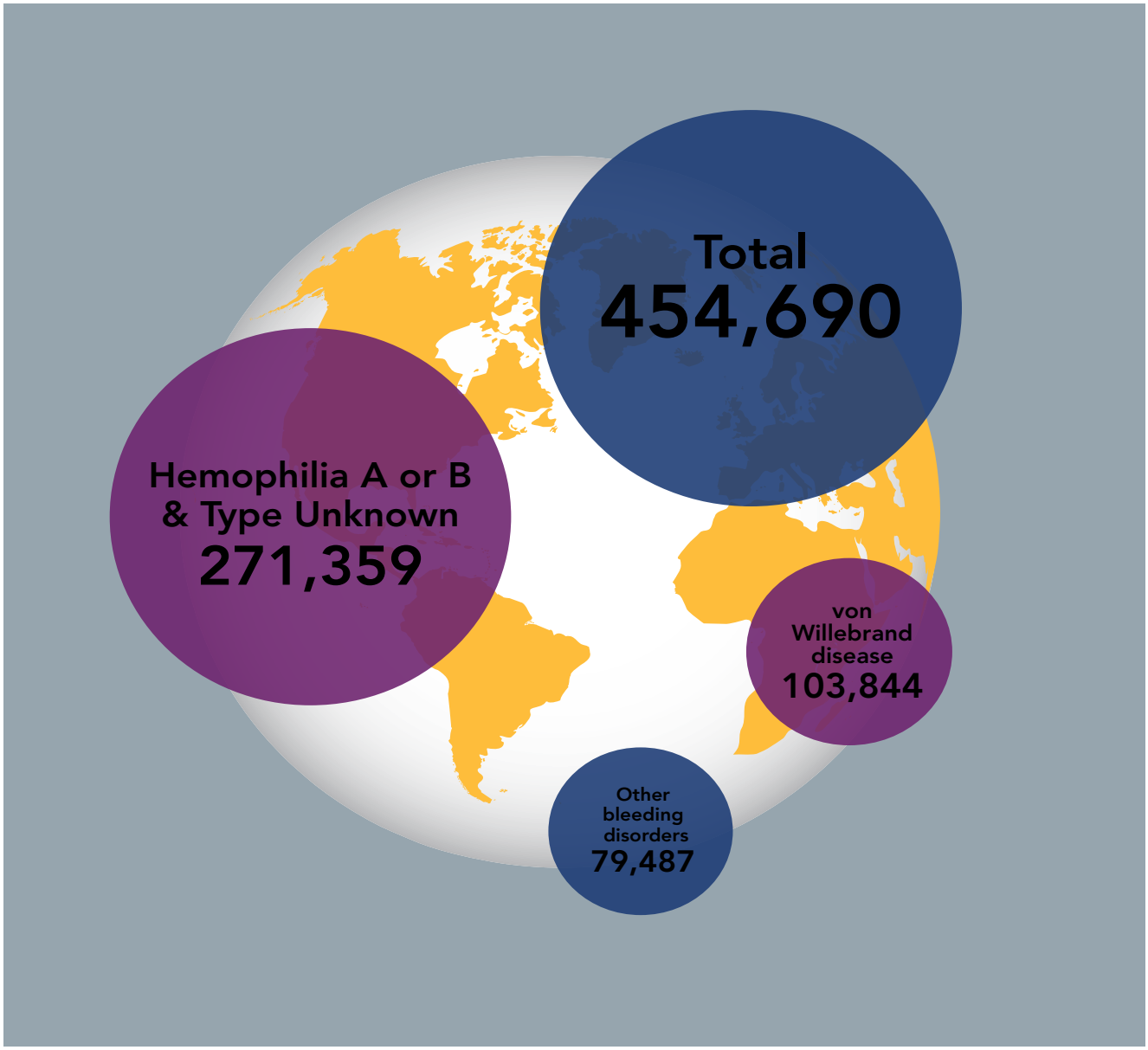
WORLD FEDERATION OF HEMOPHILIA

INTRODUCTION TO THE REPORT ON THE ANNUAL GLOBAL SURVEY 2022

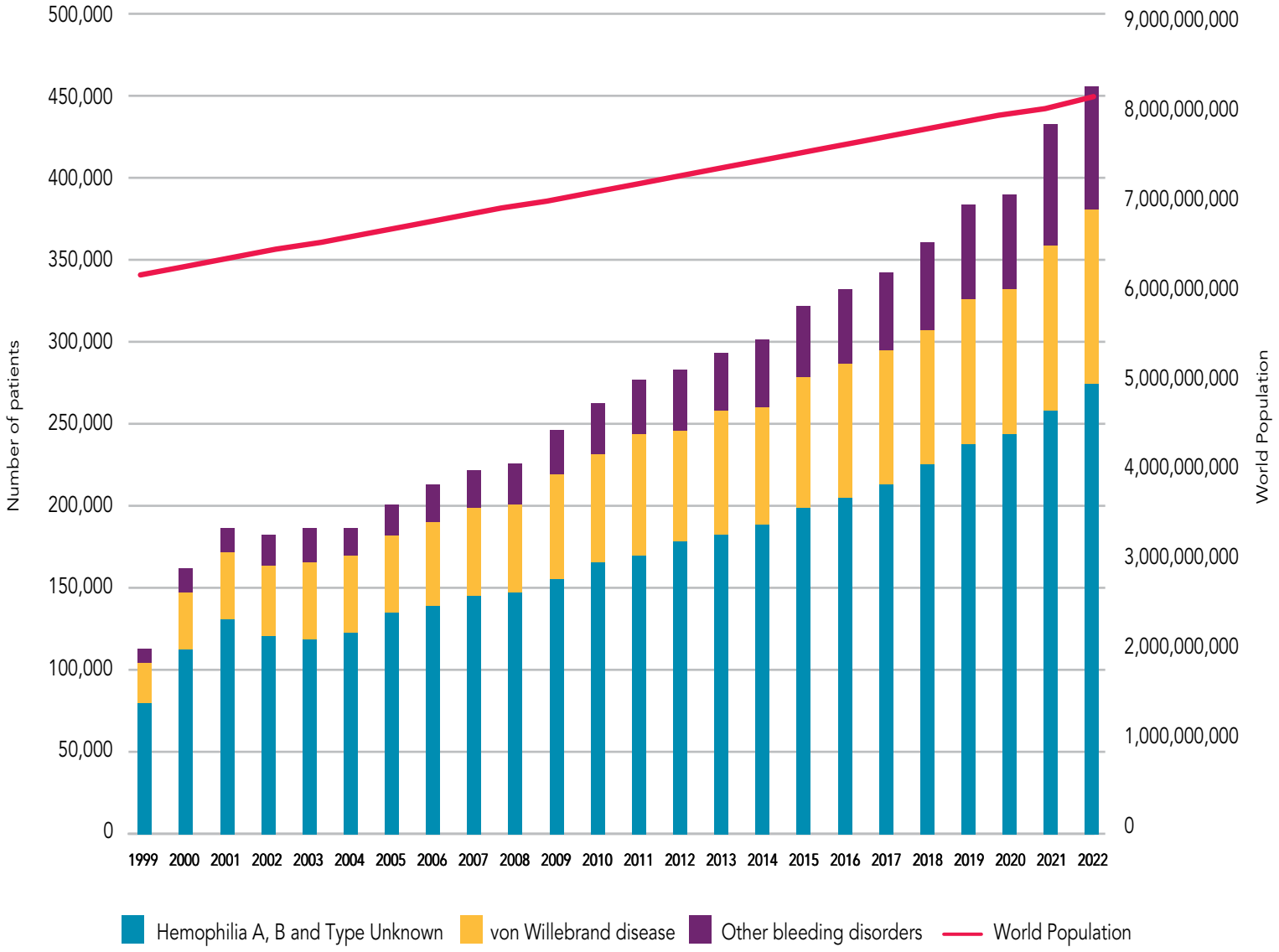
The Report on the Annual Global Survey (AGS) 2022 shows an international snapshot of hemophilia patient identification and access to care. This report includes selected demographic and treatment data on people with hemophilia (PWH), von Willebrand disease (VWD), other rare factor deficiencies, and inherited platelet disorders throughout the world. Over the
years this report has given the national member organizations (NMOs) affiliated with the World Federation of Hemophilia (WFH), healthcare providers, and policymakers an overview of the patterns and trends in hemophilia and its treatment. The annual report offers useful information to support efforts in improving or sustaining the care of people with bleeding disorders and to assist with advocacy and program planning. The WFH strives for continuous improvement every year and is appreciative of all the effort and support put forth by the NMOs.

GLOBAL REPRESENTATION
OVER TIME (1999–2022)

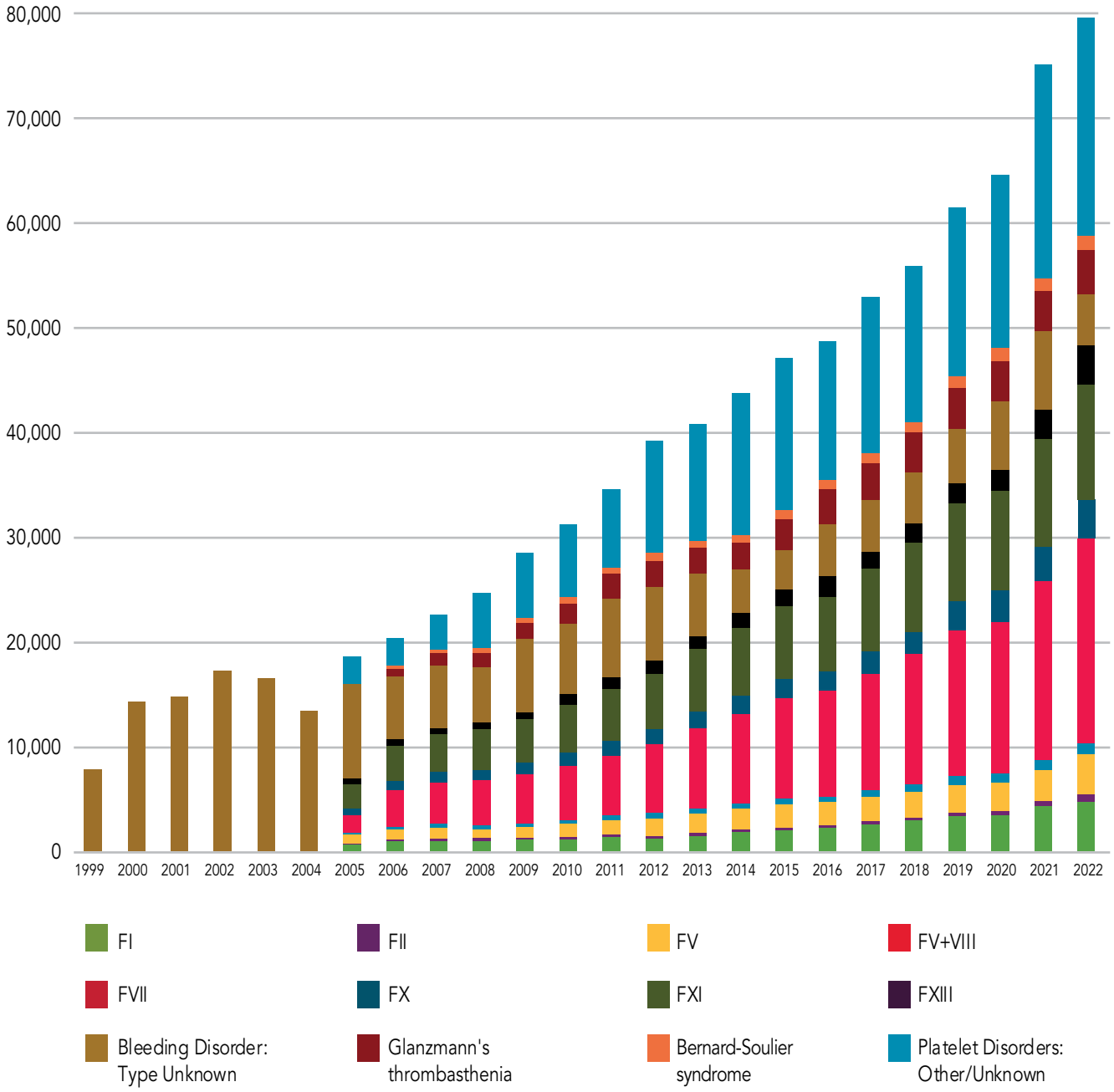
Since 1999, there have been 148 different countries that have reported data to the Annual Global Survey. This infographic contains historical data from the Annual Global Survey. That is, if a country reported data one year and not the next, the older data were used under the assumption that the number of patients did not change substantially from one year to the next. This section provides a more complete representation of the current state of patient identification globally.



Identified patients over time – all bleeding disorders



Identified patients over time – other rare bleeding disorders



KEY NUMBERS FROM THE REPORT ON THE ANNUAL GLOBAL SURVEY 2022

For all tables and graphs from this point onwards, the analyses were done using only data from countries that responded in 2022.

NUMBER OF COUNTRIES
in this survey

125

RESPONSE RATE
from WFH National Member Organizations

85% (125/147)

NUMBER OF IDENTIFIED PATIENTS

427,685

257,146	People with hemophilia
208,957	Hemophilia A
42,203	Hemophilia B
5,986	Hemophilia type unknown
100,505	von Willebrand disease
70,034	Other bleeding disorders

FACTOR VIII USAGE PER CAPITA

1.383 IU (0.203-4.364) Median (IQR)
102 countries

FACTOR IX USAGE PER CAPITA

0.240 IU (0.023-0.733) Median (IQR)
90 countries

WOMEN AND GIRLS WITH BLEEDING DISORDERS

COUNTRIES RESPONDING

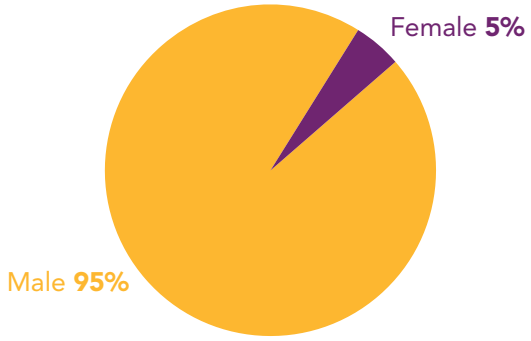
113

NUMBER OF IDENTIFIED FEMALE PATIENTS

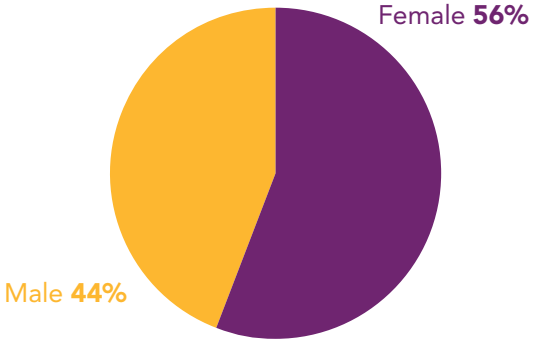
100,136

- **11,700** Hemophilia
- **54,066** von Willebrand disease
- **34,370** Other bleeding disorders

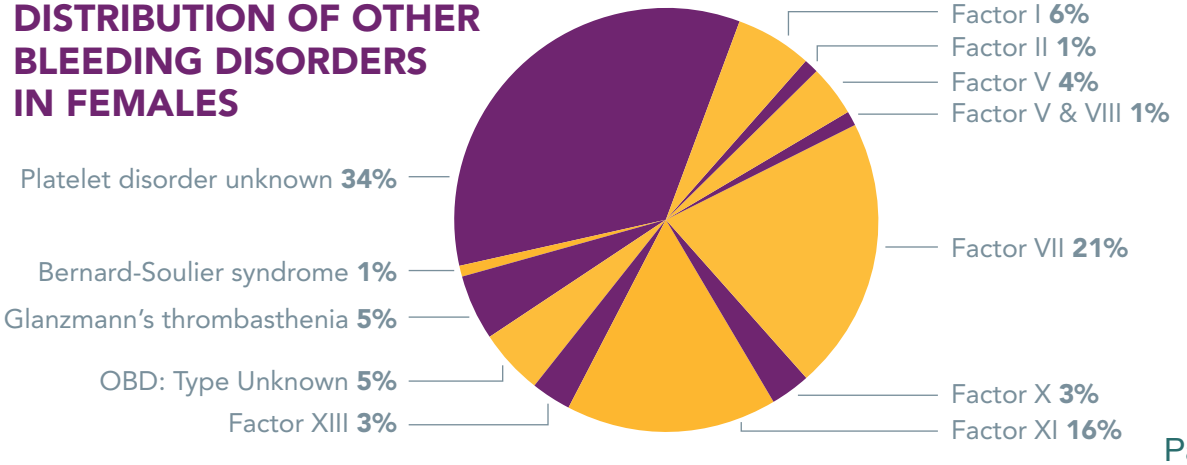
DISTRIBUTION OF HEMOPHILIA BY SEX



DISTRIBUTION OF VWD BY SEX



DISTRIBUTION OF OTHER BLEEDING DISORDERS IN FEMALES

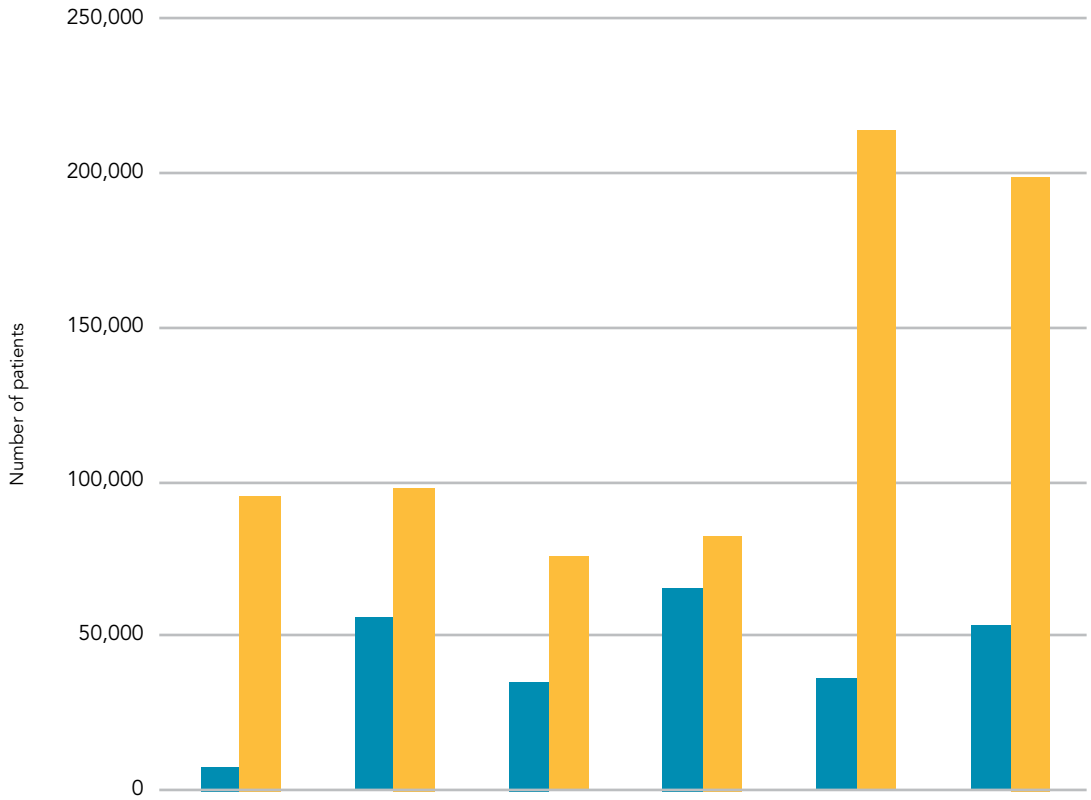


REPORT ON THE ANNUAL GLOBAL SURVEY 2022 SUMMARY DEMOGRAPHICS

Demographics

	2022 Total
Number of countries in this survey	**125**
World population covered by countries in this survey report	**7,308,554,650**
Total number of people with bleeding disorders identified	**427,685**
Number of people identified with Hemophilia	**257,146**
Number of people with hemophilia A	**208,957**
Number of people with hemophilia B	**42,203**
Number of people with hemophilia type unknown or type not reported	**5,986**
Number of people identified with VWD	**100,505**
Number of people identified with Other Bleeding Disorders	**70,034**
Number of hemophilia A patients with clinically identified inhibitors	**7,186**
Number of hemophilia B patients with clinically identified inhibitors	**385**

Number of identified vs. expected hemophilia patients by region

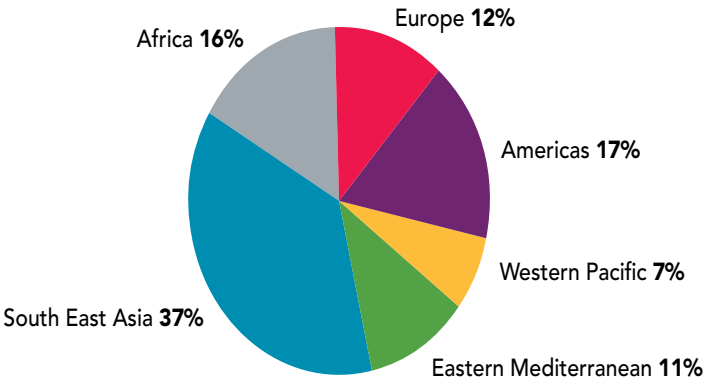


	Africa	Americas	Eastern Mediterranean	Europe	South East Asia	Western Pacific
Identified number of patients	8,003	57,954	35,576	65,632	36,648	53,333
Expected number of patients	94,130	100,085	75,318	81,981	213,492	198,738
Percent of identified patients	**9%**	**58%**	**47%**	**80%**	**17%**	**27%**

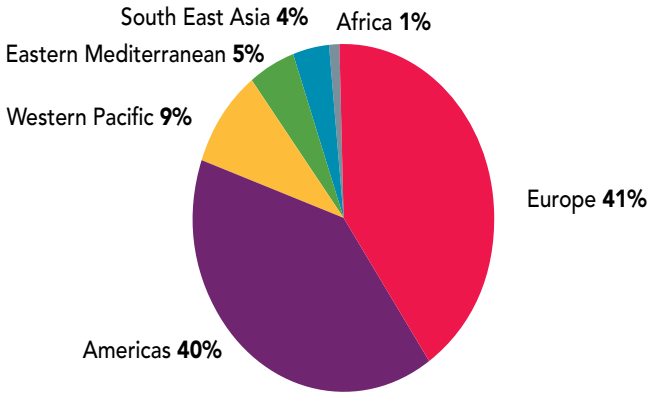
This graph was created by calculating expected number of patients using the prevalence of 20.9 per 100,000 males in hemophilia.[7]

Global distribution of factor VIII use

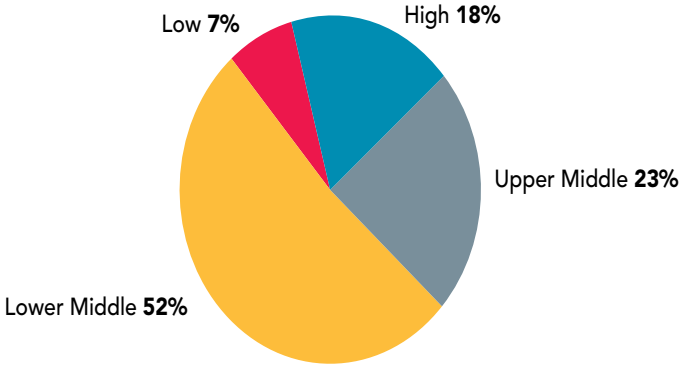
Population by region



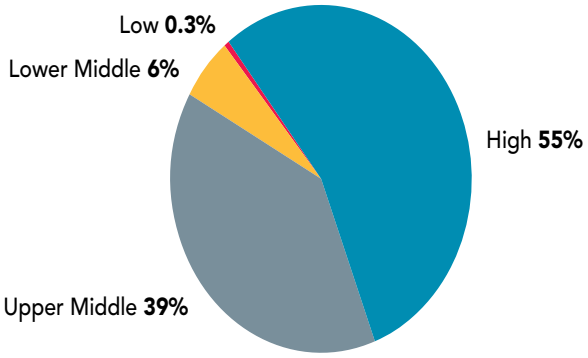
Total FVIII IU by region



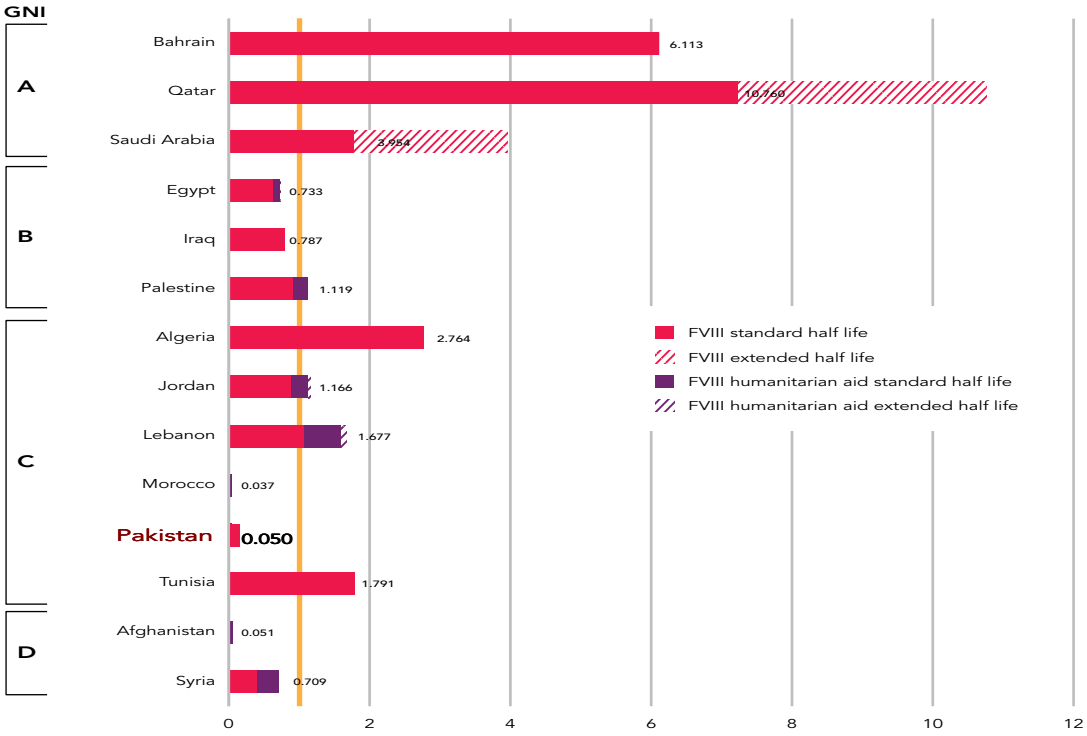
Population by gross national income



Total FVIII IU by gross national income



Mean per capita factor VIII use in Pakistan 2022 – regional and GNI comparisons of IU/total population: Eastern Mediterranean



Bernard-Soulier syndrome: A severe congenital bleeding disorder characterized by thrombocytopenia and large platelets, due to a defect in the platelet glycoprotein 1b/V/IX receptor.

Cryoprecipitate: A fraction of human blood prepared from fresh plasma. Cryoprecipitate is rich in factor VIII, von Willebrand factor, and fibrinogen (factor I). It does not contain factor IX.

Extended half-life factor concentrate: A new generation of recombinant factor concentrates, which extend their half-life. Half-life is the time it takes for an infused factor to lose half of its potency. Traditional factor VIII has a half-life of 8 to 12 hours; an extended factor VIII half-life is defined as a ratio greater than 1.3-fold, of the traditional half-life.

Factor concentrates: These are fractionated, freeze-dried preparations of individual clotting factors or groups of factors derived from donated blood.

G**lanzmann's thrombasthenia:** A severe congenital bleeding disorder in which the platelets lack glycoprotein IIb/IIIa, the blood platelet count is normal, but their function is very abnormal.

Hemophilia A: A condition resulting from factor VIII deficiency, also known as classical hemophilia.

Hemophilia B: A condition resulting from factor IX deficiency, also known as Christmas disease.

Hemophilia treatment center: A specialized medical center that provides diagnosis, treatment, and care for people with hemophilia and other inherited bleeding disorders.

Identified person: A living person known to have hemophilia, von Willebrand disease, or another bleeding disorder.

Inhibitors: A PWH has inhibitors when the body's immune system attacks the molecules in factor concentrate, rendering it ineffective.

International Unit (IU): A standardized measurement of the amount of factor VIII or IX contained in a vial. Usually marked on vials as 250 IU, 500 IU, 1000 IU, or 2000 IU.

Mild hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity below normal but above 5% of normal activity in the bloodstream. (National definitions differ on the upper limit for mild hemophilia, ranging from 24% to 50%. The normal range of factor VIII or IX is 50 to 200%)

Moderate hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity between 1 to 5 % of normal activity in the bloodstream.

Plasma-derived products: Factor concentrates that contain factor VIII or IX that have been fractionated from human blood.

PWH: Person with hemophilia

Recombinant products: Factor concentrates that contain factor VIII or IX that have been artificially produced and are,

therefore,
not derived from human blood.

Registry: A database or record of identified people with hemophilia or inherited bleeding disorders. A registry includes information on personal details, diagnosis, treatment, and complications.

Severe hemophilia: Condition resulting from a level of factor VIII or factor IX clotting activity of less than 1 % in the bloodstream. **von Willebrand disease (VWD):** An inherited bleeding disorder resulting from a defect or deficiency of the von Willebrand factor.

Mean per capita factor IX use in Pakistan 2022 – regional and GNI comparisons of IU/total population: Eastern Mediterranean

ADMIN

- Mr. Raheel Ahmed-Founder & ceo
- Mr. Arif Jamal- I.T & Administration
- Dr Sarfaraz Hussain Jafry-Director Project development &
- Training Mr. Umair Baig-Community Compliance Manager
- Mr. Abbas Ali Zaidi-HR Manager
- Mr. Ayaz Ali-Finance Assistant
- Mufti Umair Raees-Sharia Compliance Officer

MEDICAL TEAM

- Dr Munira Borhany - Professor Hematologist Dr
- Noman - Physician
- Dr Nida - Physician
- Dr Heeba Qureshi - WBDR research
- Mrs Shumaila - Staff Nurse
- Dr Maleeha Zahid - Physiotherapist
- Mrs. Sidrah Umair - Registry Department
- Mr. Johnson Javed - Staff Nurse
- Miss Farkhanda Francis - Phlebotomist
- Mr Usman - Phlebotomist
- Dr Shoukat - Physician

BLOOD BANK

- Syed Mubeen Shah - Lab and Blood Bank Tech
- Shahrukh Ahmed Khan - Product Inch
- Imran - Lab & Blood Bank Tech
- Daniyal Wajid - Product Incharge

RECEPTION

- Muhammad Raheel - Data Putter/reception

DATA ANALYSIS

- Noorulhira - Data Analysis / handling international portals

SHARIYAH DEPARTMENT

- Dr. Mufti Asim Ali Khan - Sharia compliance officer
- Mufti Muhammad Raees - Sharia Advisor

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ZAKAT ACCOUNT	
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Account Number	: 0236586002000023
IBAN Number	: PK94SUMB0236586002000023

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