

Living Life to the Fullest

Hemophilia = Unity, Care and Treatment



Hemophilia Society Mumbai (Chapter)

31st Annual Report 2022 - 2023

MESSAGE FROM PRESIDENT



Mr. Ajay Palande
President of HSMC

Dear Friends,

I hope this message finds you well. As Diwali approaches, I want to take a moment to extend my warm wishes for a Happy Diwali in advance.

Due to some critical health issues, I have been unable to serve the Hemophilia community at HSMC for the past year and a half. After dedicating over 18 years to this cause, I've decided to take a break to focus on my health. I am grateful for the care and support provided by the medical team and my fellow volunteers. With your blessings and if fate allows, I hope to return to serving the Hemophilia community soon.

Thank you for your understanding and continued support.

MESSAGE FROM VICE PRESIDENT



I hope this message finds you all in good health and high spirits. I extend my heartfelt gratitude for being part of our wonderful community of patients, doctors, and dedicated caregivers who come together with a common goal – the overall development of our community.

In this journey, our new Hemophilia Treatment Center (HTC) introduced recently is making remarkable progress, while our existing center continues to provide essential care to our patients. These two centers have significantly enhanced patient care, providing more options for those living with hemophilia. Additionally, we've established a third center, specifically for pediatrics, to ensure that our young patients receive specialized care.

During this period, we've extended our support to many patients through all three HTCs and on a personal level as well. This fills me with pride, knowing that I am part of this remarkable team. Our consistent lobbying efforts continue to bring advanced treatments and medicines to more centers, expanding the reach of high-quality care. Our engagement with the government remains unwavering, ensuring a regular supply of essential medications, not only for our chapter but for the entire region. This year, our focus has been on organizing activities like The Unity Youth Camp, held at Uttan, which included a plethora of engaging events and informative doctoral sessions. We have also been dedicated to organizing Patient Education Programs, Save One Life sponsorships, monthly grocery assistance for needy families, and providing factor support, among other activities, which we intend to continue. I would like to express my sincere gratitude to the entire Hemophilia fraternity, including patients, doctors, caregivers, and generous donors, for standing by our side and becoming a part of our extended family.

Mr. Krunal Kotecha
Vice President of HSMC

MESSAGE FROM DOCTORS



It gives me a sense of great honour to write this message for one of the most active self- help NGOs in the country, which is run by and for the persons with Hemophilia (PwH). It is indeed commendable that since its establishment in 1993, the society has been ever growing in terms of bringing under its umbrella, till date over 1200 PwH and other bleeding disorders. The society has been a mouthpiece for successfully representing the difficulties faced by the PwH to the policy makers. The remarkable improvement in the availability of clotting factor concentrates, organizing camps for inhibitor screening and carrier diagnosis, patient counselling for prenatal diagnosis, providing free medicine, arranging therapist home visits, rehabilitation activities, etc. are some of the results of the united

efforts made by the society and its members. The society has also been organizing several non-academic fun activities to keep the PwH and their families motivated. Under a very able National and local leadership, the young at heart, enthusiastic, creative, and passionate team of office bearers and volunteers are always ready to take on any responsibility of the HFI, and execute it with a smile. I congratulate the society for their noble work and wish them best for their continuing efforts for the betterment of hemophilia community.

Dr. Bipin P. Kulkarni
Ph.D., MNAMS

*Scientist D / Assistant Director, Head Department of Haemostasis and Thrombosis
ICMR- National Institute of Immunohaematology Parel, Mumbai- 400012.
Director, WFH- International Hemophilia Training Centre (IHTC), Mumbai.*



Dear Members of the Haemophilia Society,

I regret missing the annual meeting due to a family emergency. As a surgeon, I've seen the challenges faced by hemophilia patients during surgery. Collaborating with the Hemophilia Society is crucial for improving care through interdisciplinary teamwork, knowledge sharing, and innovative approaches. I appreciate your work and look forward to enhancing care for hemophilia patients together.

Dr Mahadeo N Garale
*Associate Professor
Department of General Surgery*

MESSAGE FROM DOCTORS



Dear Mumbai Chapter,

I wish you the very best in your endeavours to support all PwH and other bleeding disorders living in Mumbai and its environs. I speak for the K J Somaiya Super Specialty Hospital & Research Centre team and it gives me immense pleasure to work with you in order to achieve our common goals as we are equal stakeholders in this mission. Working and dreaming together for a bleed free and pain free Life for all PwH is the ultimate purpose and ambition that we will strive to achieve. Let's embark on this journey together and reach our destination soon.

Kind Regards,

Dr. Savita Rangarajan, Dr. Shrimati Shetty, Dr. Nimish Kulkarni, Dr. Shrinath Kshirsagar, Dr. Shweta Bansal, Manisha Bobade (CEO), & the CTRU Team

Dr Savita Rangarajan

*MBBS, MD, FRCP, FRCPATH
Consultant Hematologist*



Management of hemophilia has progressed a lot. Even in India management has improved progressed with many patients getting prophylaxis and newer therapies such as emicizumab care in hemophilia has progressed to approval of gene therapy in hemophilia A and B.

Wishing you all hemophilia bleed free treatment and happy healthy life.

Dr Chandrakala

*Professor & Head,
Dept of Clinical Hematology
KEM Hospital*



Greetings from Department of Dentistry, KEM Hospital.

Management of oral bleeds and diseases in the hemophiliacs is now routine owing to the extraordinary efforts put in by the HSMC. Also patients are quite aware and now demand saving their problematic teeth considering the benefit to risk ratio.

From a least invasive procedure like fillings to complex surgical extractions, varied dental treatments are performed, regardless of the inhibitor status under meticulous replacement therapy. It has always been learning, procuring and applying new concepts and techniques for the betterment of hemophiliacs. Almost 2/3rd of our patients are children who are highly benefited as their milk teeth are

saved to serve till they get the permanent ones. To add on we have got a few publications that might help create awareness amongst our fellow dentists in managing such patients.

Our department will continue striving for the amelioration of the hemophiliacs.

Dr Nanda Pai

*Professor and HOD, Dept of Dentistry
Seth G S Medical College and KEM Hospital, Parel*

QUICK UPDATES

Membership as on 31st March 2023:

Total 35 new members registered during the year from 1st April 2022 to 31st March 2023. As on 31 March 2023, **Total Registered Members: 922**

Anti Hemophiliac Factor Consumption:

Year	Factor VIII		Factor IX		FEIBA		Novo 7	
	2022-23	2021-22	2022-23	2021-22	2022-23	2021-22	2022-23	2021-22
Paid	84,250 i.u.	28,250 i.u.	3,600 i.u.	3,600 i.u.	—	—	—	—
Donated	9,590 i.u.	9,152 i.u.	85,160 i.u.	18,960 i.u.	4,500 i.u.	34720 i.u.	6 mg	—
Total	93,840 i.u.	37,402 i.u.	88,760 i.u.	22,560 i.u.	4,500 i.u.	34720 i.u.	6 mg	NIL

Kem Hospital Diagnosis Of Factor Deficiency & Test Report

ICMR- NIIH: Dept. of Haemostasis & Thrombosis

Carrier detection in hemophilia A, B and other bleeding disorders:

In the current year 89 females (79 haemophilia A, 10 haemophilia B) were referred for the detection of carrier status. The analysis was performed by inverse PCR for intron22 and 1 inversion in F8 and direct sequencing of the coding regions of the respective genes, NGS and MLPA. 51 females were found to be carriers whereas 38 females were non carriers.

Genetic diagnosis of hemophilia A:

Genetic diagnosis of 15 Hemophilia A, Hemophilia B, vWD, F7, F10 deficient patients referred to us from various canters in India was successfully carried out. The analysis was performed by inverse PCR for intron 22 and 1 inversion in F8 and direct sequencing of the coding regions of the respective genes.

First trimester antenatal diagnosis of Hemophilia A and B by chorionic villus sampling procedure:

In the current year, total 75 females were referred to us for first trimester antenatal diagnosis of Haemophilia A, B, VWD. 58 females belonging to haemophilia A families and 12 females belonging to haemophilia B families, 2 VWD families, 1 FXIII family, 1 afibrinogenemia and 1 F7 family were referred in the first trimester for prenatal diagnosis. 59 fetuses were found to be unaffected whereas 16 were affected. Methods used for analysis were same as that used for carrier detection.

Factor Assay done for 3536 and Inhibitor Screening done for 696 persons with bleeding disorder, out of which the data of PwH is presented here.

	Factor VIII	Factor IX	Factor VII	vWD	Rare Factor
Severe	65	13	—	55	7
Moderate	20	10	1	—	2
Mild	25	5	7	—	9
Inhibitor Positive	228	4	—	—	—

FINANCIALS

THE BOMBAY PUBLIC TRUST ACT, 1950
SCHEDULE VIII
VIDE RULE 17 (1)

Name of the Public Trust : Hemophilia Society Mumbai (Chapter)

Registration No : F - 17067

BALANCE SHEET AS AT 31st MARCH 2023

FUNDS & LIABILITIES	AMOUNT (Rs.)	AMOUNT (Rs.)	PROPERTY & ASSETS	AMOUNT (Rs.)	AMOUNT (Rs.)
TRUST FUNDS OR CORPUS :			Immovable Properties :		
Balance as per last Balance Sheet	718,309.50		(Common Schedule "G")		575,211.67
Add Received during the year	-		Movable Properties :		
Less Adjustment during the year	-	718,309.50	(Common Schedule "G")		116,150.81
Life Membership Fees			Investments :		
Opening Balance	1,683,200.00		Bank Fixed Deposits (Schedule "H")		13,363,616.87
Add Additions During the year	82,500.00				
Less Written off as not recoverable	-	1,765,700.00			
Other Earmarked Funds : (Schedule "E")			AMOUNT RECEIVABLES :		
(Created under the Provision of the the trust deed or scheme or out of the Income)			Loans (Schedule "I")		
a) Fund for Area-wise Therapist - PWH Meeting	102,237.84		Sundry Debit balances	293,109.00	293,007.25
b) Fund for HCV Treatment	159,612.00			1,898.25	
c) Nurse Project - India Fund	15,100.00				
d) Screening & Laboratory of PWH - NOVO	577.00		Advances & Other Deposits (schedule "J"):		
e) Education Fund	145,887.00		TDS	254,198.05	
In Rural Area -	70,299.00		Accrued Interest on Bank FDR's	233,568.01	
f) Hemophilia Care Centre Fund	3,373,370.00		Advances Others	2,183.00	489,949.06
g) Entrance Fees	166,600.00	4,033,682.84			
			Cash and Bank Balances :		
Loans (Secured or Unsecured):			a) In Current A/c with		
From Trustees	-		Bank Balance (Schedule "K")	1,902,769.28	
From Others	-		b) Cash in hand	5.00	
			With the Trustee	3,806.13	1,906,580.41
			With the Manager		
Liabilities :					
For Expenses - Schedule "F"	47,200.00				
Members	1,837,102.53				
Amount Set Apart	350,000.00	2,234,302.53			
Income & Expenditure Account :					
Balance as per last Balance sheet	7,789,875.36				
Less Appropriation, if any	Nil				
Add Surplus/Deficit (As per Income and Expenditure Account)	204,645.85	7,994,521.20			
		16,746,516.07			16,746,516.07

As per our report of even date attached.
For S.P. Gupta & Associates
Chartered Accountant
Firm Registration No : 103445W

For HEMOPHILIA SOCIETY MUMBAI (CHAPTER)

HEMOPHILIA SOCIETY MUMBAI (CHAPTER)

Shashikant.P.Gupta
Partner
Membership No : 031899
Mumbai

29 SEP 2023



For
PRESIDENT / SECRETARY / TREASURER
TRUSTEES

FINANCIALS

THE BOMBAY PUBLIC TRUST ACT, 1950
SCHEDULE IX
VIDE RULE 17 (1)

Name of the Public Trust : Hemophilia Society Mumbai (Chapter)

Registration No : F - 17067

INCOME & EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31ST MARCH, 2023

EXPENDITURE	AMOUNT (Rs.)	AMOUNT (Rs.)	INCOME	AMOUNT (Rs.)	AMOUNT (Rs.)
Expenditure in respect of properties :			(accrued)		
Rates, Taxes, Cesses	-		By Rent -----		
Repairs & maintenance	-		(realised)		
Salaries	-		(accrued)		
Insurance	-		By Interest -----		
Depreciation	-		(realised)		
(By Way of provision of adjustment)	-		(Schedule " C ")		
Other Expenses	-		On Bank FDR's		
			On Loans		
			On GOI Bonds		
			On Bank Account's		
			On Debentures		585,080.19
Establishment Expenses (Schedule "A")		649,193.09			
Remuneration of Trustees			By Dividend		
Legal Expenses & Professional Fees					
Audit Fees		64,510.00			
Amount Written off :			By Donations & Contribution Received		
a) Amount Written off	-		(Schedule " D ")		2,075,477.13
b) Loan Scholarship	-				
c) Irrecoverable Rents	-		By Income from other sources		
d) Other Items	-		(in details as far as Possible)		
			- Service Charges		
			- Sale of Scrap		
Miscellaneous Expenses			By Amount Recovered		
Depreciation		87,037.45	a) Provision for Doubtful Debts Reversed		
Amount transferred to reserve for Doubtful debts			b) Contribution written off earlier now recovered		
Expenditure on object of trust :					
a) Religious					
b) Educational	11,200.00				
c) Medical Relief	1,036,092.93				
d) Relief of Poverty	141,019.00		By Excess Provision Written Back		
e) Other Charitable Objects					
(Schedule "B")	466,859.00				
		1,655,170.93			
Surplus Carried over to Balance sheet		204,645.85			
		2,660,557.32			2,660,557.32

As per our report of even date attached.

For S.P. Gupta & Associates

Chartered Accountant

Firm Registration No : 103445W

S.P. Gupta

Shashikant P. Gupta

Partner

Membership No : 031899

Mumbai

Date **29 SEP 2023**



For HEMOPHILIA SOCIETY MUMBAI (CHAPTER)

HEMOPHILIA SOCIETY MUMBAI (CHAPTER)

Pratik L. Mehta
PRESIDENT / SECRETARY / TREASURER
TRUSTEES

MEETING CARD

Report of Executive Committee Meetings:

From 1st September 2022 to 31st August 2023, total 6 executive committee meetings was conducted for planning and executing society's activities.

Name	Designation	Present	Absent
Mr. Ajay Palande	President	1	5
Mr. Krunal Kotecha	Vice President	4	2
Mr. Paresh Parmar	Hon. Secretary	6	0
Mr. Mahesh Mundra	Jt Secretary	4	2
Mr. Jigar Kotecha	Jt Secretary	5	1
Mr. Pratik Mehta	Treasurer	6	0
Mr. Rupal Panchal	EC Member	0	6

Name	Designation	Present	Absent
Mr. Kalpesh Patil	EC Member	2	4
Mr. Raju Dhobi	EC Member	4	2
Mrs. Veronica Correia	EC Member	4	2
Mr. Yatish Patali	EC Member	5	1
Mr. Mustafa Shaikh	Youth Group Representative	1	5
Mrs. Runa Bera	Women Group Representative	1	5

AGM of HSMC Last Year:

We have conducted our 30th Annual General Meeting on 30th Oct'2022 at CVTC Auditorium. Total 45 PwH attended this Annual General Meeting with EC members, staff of HSMC, guest Mr. Balshiram Gadhave(RCC), Ms. Indira Nair (Women Group Chairperson, HFI) and Dr. Devila Sahu (Founder). Mr. Krunal Kotecha (Vice President) welcomed all attendees. The meeting was hosted by Mr. Paresh Parmar (Hon. Secretary). All agendas were discussed and passed by the house. AGM ended with vote of thanks.



AGM of HFI Last Year :

The Annual General Meeting 2022 of HFI is held at Delhi on 24th & 25th of September 2022. From Mumbai Chapter Mr. Paresh Parmar, Mr. Jigar Kotecha, Mr. Krunal Kotecha, Mr. Pratik Mehta, Mr. Mahesh Mundra, Mr. Raju Dhobi and Mr. Kalpesh Patil attended the HFI AGM. Our Jt. Secretary Mr. Jigar Kotecha contested for the post of EC Member in HFI election which he lost by just 1 Vote, but he won heart of everyone on national level.

ACTIVITY REPORT

Gene Therapy - A Newer Treatment in Hemophilia:

Hemophilia Society Mumbai (Chapter) had successfully organized an educational program "Advancement in Hemophilia Treatment" at Somaiya Hospital on 2nd of October 2022.

Dr. Savita Rangrajan explained Gene Therapy and other New Treatments available for Hemophilia. Dr. Shrimati Shetty and Dr. Shweta Bansal described a few important points regarding Factor assay and Inhibitor.



Youth Group & Women Group of HSMC, 02.10.2022:

Hemophilia Society Mumbai Chapter Youth and Women's group joint meeting and also celebrated Youth and Women 11th anniversary.



Financial Empowerment for Women:

We received a project through Ms. Indira Nair for Financial Empowerment Grant from Baroda Shakti. We were granted a project of Rs. 78,000/- for few of our needy women members from Mumbai Chapter. Baroda Shakti Team helped in financial empowerment of 6 needy women members from Mumbai Chapter by providing 4 flour Mill machines and 2 full shuttle sewing machines. We also received sanitary napkins for needy members. Special thanks to Baroda Shakti Team and Mrs. Indira Nair.



ACTIVITY REPORT

Doctor's Appreciation on Occasion of Diwali:

On the Diwali occasion, HSMC Executive members meet doctors and nurses from KEM Hospital, Thane Civil, Somaiya Hospital and DHS. We have distributed Gifts and greeted each other. We are so thankful for all their support in Hemophilia Treatment.



Children's Day Celebration:

Hemophilia Society Mumbai Chapter celebrated Children Day with Hemophilic kids on 14th November 2022 at Chembur. Children enjoyed game and crafting. Party ended with group pictures followed by yummy snacks and lovely smiles on face of little Kids.



ACTIVITY REPORT

WFH Delegates Visits Mumbai IHTC:

Mr. Cesar Garrido - President, WFH, Dr. Assad Haffar - Director, Humanitarian Aid Program, WFH, Ms. Salome Mekhuzla - Director, Global Development, Mr. Harshal Kale - Regional Manager, South Asia & East Asia, WFH visited Hematology department Ward 42, Orthopaedic department, Dental Department, Occupational Therapy Department, ICMR Department and Hemophilia "Day Care Center" K.E.M Hospital on 2nd Dec'2022. There we had an intrusting interaction session with delegates and Doctors. Meeting with all department presentation presented by the Dr. Aditi Shah, Assistant Professor, Department of Clinical Hematology, KEM hospital.

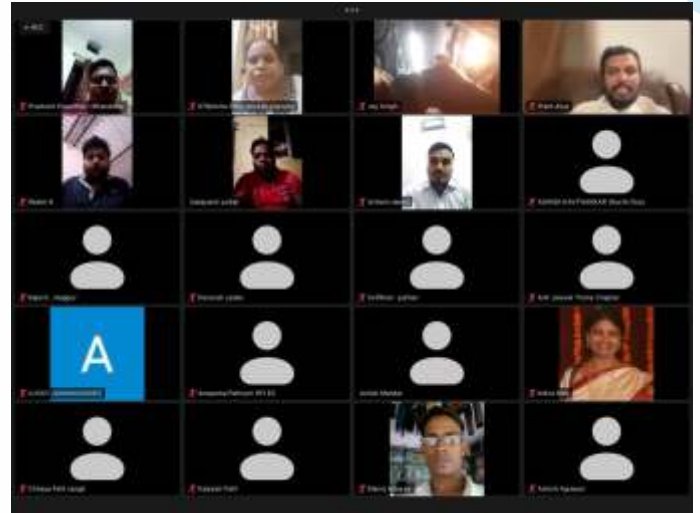
Mumbai Chapter & Thane Chapter Committee members, welcome our guests with Indian tradition and felicitate to guests and Doctors with flower & Gifts. Dr. Assad Haffar interacted with hemophilia on their issues and meet each and every hemophilia patient admit in KEM hospital and discuss about treatment. The meeting ended with snacks.



ACTIVITY REPORT

Webinar on Tools for Advocacy:

Hemophilia Federation of India & Hemophilia Society Mumbai Chapter is jointly has organized a webinar virtually on Zoom meet application for "Discussion on Tools For Advocacy" on 10th of December 2022 lead & plan by Dr Vyankatesh Parlikar with help of HFI Team & HSMC Team and invited to all hemophiliacs of Maharashtra as well Maharashtra chapters key persons. In this meeting we discuss about achieve our goal "One Nation One Treatment, Prophylaxis for All".



Christmas Celebration with CwH

We are pleased to report that on 17th December 2022, HSMC Women's group had celebrated Christmas party with Women, children and Committee members at our HSMC, Parel, Mumbai. Various games for Women and children were kept. Around 45-50 women, EC Member and children in all were present. Ms Indra Nair, Chairperson of women group, HFI , was also present. All were very enthusiastic to take part in games and Carol singing. Most of the participants were wearing red and white and Santa cap. Prizes were given to the winners. Santa also gave the gifts to the children. Snacks were served during the function. All in all everyone enjoyed the celebration and left with happy note.



ACTIVITY REPORT

State Advocacy Workshops at Mumbai:

These meetings were held to discuss state level advocacy efforts and importance of state-wise advocacy committee. The key opinion leaders of local chapters of the state attended.



Education Help to PwH:

Shri. Nilotpal Mrinal, founder Nanni goonj, social worker was organized a program for education help to Divyang persons on the memory of late Shri Sushant Singh Rajput on his birth anniversary. Our five hemophiliac children got education help through Mr. Yatish Patali.



Women's Meeting and Haldi Kumkum Event:

On occasion of Makar Sankranti, HSMC, Mumbai women group celebrated Haldi Kumkum program on 24th January 2023 at HSMC Office. Around 15 women were present on this occasion. After introduction and some sharing their experiences about handling Hemophilia, quite a few women shared that such meetings are required to lessen their stress.



ACTIVITY REPORT

Haldi kumum was put up and each one took their spouses name by saying Ukhana . Snacks were served and some wan (give away) were exchanged. All women present were informed about filling the Google forms on urgent basis, giving information about their children who are suffering from Hemophilia. Meeting ended with vote of thanks.



Awareness and Fund Raising Program:

Arya Vidya Mandir school at Bandra Kurla Complex had organised "Arya Prabha Diwas" on 13th February'2023 for this they invited our CwH between 8 to 12 age group. Our 32 children and their parent's total 66 people along with HSMC staff participated in the event.

AVM school management organized pooja for our hemophiliacs better health. Our children enjoyed the dance and various games arranged by the students from AVM. All our children were accompanied by the students from AVM. After the games, the children enjoyed delicious food. Each child received a gift. We also received donation cost of Rs. 20,000/- medicines.



ACTIVITY REPORT

SOL Meeting & Fund Distribution:

On the 18th of February 2023, a meeting with SOL beneficiary, HSMC EC members and staff successfully conducted at the HSMC office to distribute funds.

We distributed funds to all 33 Nos. Of SOL Sponsorship beneficiaries and the meeting ended with delicious snacks.



International Women Day Celebration:

HSMC Mumbai celebrated Women's day Program on Sat 11th March, 2023 at our HSMC Parel Office. Mr Valerian Pais, Asst Director - Commercial, HelpAge India was the Guest Speaker on this Occasion. He spoke in Women Empowerment. He described How we should apply 4 Cs (Contribution, Communication, Consideration and Comparison) are important to be Happy and successful in life. He also described about how HelpAge India helps Sr Citizens in various ways. They have mobile vans everywhere across the cities to have free medical aid for various diseases like diabetes, Blood Pressure, joint pains etc. Also they do free cataract surgery to the elderly people. Many women asked him various questions on health which he satisfied everyone with reply. The guest was very happy to be in our HSMC and expressed his Happiness about our work culture. He has assured to join hands with us. The meeting ended with vote of thanks and distribution of snacks and giveaways to Women.



ACTIVITY REPORT

Hemophilia Awareness; 25.04.2023:

Mr. Jigar Kotecha Jt. Secretary of the Hemophilia Society Mumbai Chapter gave information about hemophilia disease to The Week Magazine during hemophilia awareness month. Also, they informed about newer treatments of hemophilia. We share press release link with you.

Link:

<https://www.theweek.in/news/health/2023/04/25/india-is-home-to-second-largest-population-of-patients-living-wi.html>



World Hemophilia Day Celebration:

Hemophilia Society Mumbai Chapter celebrated World Hemophilia Day on 30th April at KEM Hospital. Program started with breakfast & registration. We had a patient education program where Dr. Bipin Kulkarni (HOD ICMR) provided guidance on Carrier detection and Prenatal Diagnosis. Dr. Chandrakala (HOD Hematology) has guided PwH on treatment and clinical trials. We had Dr. Nanda Pai (HOD Dentistry). Dr. Shraddha Kamble & Dr. Papiha Chavan (Occupational Therapist) On Behalf Of Dr. Kirti Kene Patil Guided on how to maintain the joints and muscles and also explained about importance of physiotherapy. Dr. Mahadeo Garade (Surgery Dept) explained how smooth surgeries are being performed on Hemophiliac with help of hematology department. We had special Guests Mr. Nilotapal Mrinal (BJP Karyakarta), and Mr. Sameer Wankhede (IRS Officer) along with his wife Ms. Kranti Redkar (Marathi Actress), they motivated Youth and assured us to help our Community for Education and guidance on UPSC exams and many other exams for coming in public services. We have done felicitation of 14 CwH for Excellence in their Education. An entertainment program was arranged which was enjoyed by an audience of all ages. After entertainment program finished, everyone had delicious lunch organized by Mumbai chapter.



ACTIVITY REPORT

Inauguration of "Multidisciplinary Hemophilia OPD":

In collaboration with the Hematology and ICMR departments, we inaugurated a specialized Hemophilia Outpatient Department (OPD) known as the "Multidisciplinary Hemophilia OPD." Our sincere gratitude goes to the medical professionals involved, notably Dr. Chandrakala and her team, as well as Dr. Manisha Madkaikar, Dr. Bipin Kulkarni, and their respective teams, along with Dr. Sangeeta Ravat, the Dean of KEM Hospital, for their contributions to the enhancement of Hemophilia care.

After extensive deliberation, we have reached a consensus to host a comprehensive panel of doctors during this special Hemophilia OPD, which will take place every Wednesday at our Day Care center from 11 am to 1 pm. The primary objective of this OPD is to collectively identify patient issues and provide prompt resolutions with the presence of highly qualified doctors on the panel. Furthermore, we are planning to utilize BMC funds to support advanced treatments such as Hemlibra and similar therapies for our patients. This initiative is expected to significantly enhance the overall care provided to individuals with Hemophilia, thereby improving their physical well-being.



Advocacy Update:

We are met with Mr. Bachhu Kadu MLA on dated 7th of June 2023, Mr. Eknath Shinde Chief Minister & Mr. Devendra Fadnavis Deputy Chief Minister of Maharashtra on dated 26th of July 2023 for the continuation of factor supply and request to give medicine omalizumab to our patients for their better health.

Mr. Jigar Kishore Kotecha keeps meeting Dr. Mahendra Kendre & Other Authorities for the factor's shortage very often. He has also spoken to Dr Kendre to Revise the factors distribution pattern. Because KEM being the IHTC more factors are used in KEM in comparison to other HTCs. In Details He Can Explain During The Meeting. Also, He Went to Meet Palak Mantri (Guardian Minister) to explain him about Hemophilia and its needs.

We requested to PwH/CwH on WhatsApp to raise an online grievance on "Aaple Sarkar" government portal for unavailability and shortage of factors. Our most of PwH registered their grievance on "Aaple Sarkar" government portal.



ACTIVITY REPORT

Youth / Women Get together:

Youth Group and Women Group of HSMC organized get together on the date 20th of August and 24th of August.



SOL Meeting & Fund Distribution:

On the 26th of August 2023, a meeting with SOL beneficiary, HSMC EC members and staff successfully conducted at the HSMC office to distribute funds. We distributed funds to all 33 Nos. Of SOL Sponsorship beneficiaries and the meeting ended with delicious snacks.



PwH Youth Camp:

The Unity Youth Camp 2023, organized by the Hemophilia Society Mumbai Chapter, was a resounding success. Held from September 1st to 3rd at La Shimmer Resort in Uttan, Bhayandar, the camp aimed to empower and support youth living with hemophilia. On the first day, Dr. Devila Sahoo provided valuable insights into daily exercises for managing hemophilia, while Dr. Kanjashka Ghosh offered motivation and blessings to the enthusiastic youth participants.

The second day featured informative sessions by Prasad Shinde, Jigar Kotecha, Raju Dhobi, Kalpesh Patil, Farukh, and Himashu, focusing on teaching self-infusion techniques. Additionally, two doctors from Kem, Dr. Rameshwar and Dr. Shraddha, introduced the participants to the benefits of hydrotherapy in the swimming pool. The camp fostered teamwork, self-capability development, and support among the hemophilic youth, contributing to their overall happiness and well-being.



ACTIVITY REPORT

Exciting activities and games, from balloon balancing to a memorable ramp walk, added an extra layer of enjoyment to this enriching experience. The Unity Youth Camp has proven to be a fantastic initiative, with plans for its continuation in the coming years, promising even greater youth participation and growth.



Achievements:

- Many PwH learned self-infusion during the camp.
- Participants gained knowledge of hydrotherapy and aqua therapy.
- IQ games enhanced participants' mental agility and confidence.
- The camp fostered unity and camaraderie among participants through team activities.

ACTIVITY REPORT

Major Projects:

Save One Life (SOL):

Save One Life was founded in 2000 by Laureen A. Kelley, author, president of LA Kelley Communications and mother of a son with hemophilia. We have been receiving help under Sponsorship Programme, Scholarship Fund, Micro-Enterprise Fund and Project Share since many years.

This year, under Sponsorship project total 32 from Mumbai beneficiaries received donation. Total fund received USD \$11,181.67 (Rs. 9,30,768/- Approx). This help means a lot to Hemophiliacs which was used for various needs like education, food, medicine, and lifestyle improvement.

Home Therapy:

This project is meant for those patients, who require occupation therapy. Patient who goes to therapist and after scrutinizing the patient, when therapist advise to undergo occupation therapy, then to avoid such patient's everyday travelling and unnecessary muscular pain, we have planned to initiate this project.

Under this project, therapist goes to patient's house and gives regular therapy rather than patient comes to hospital. This saves not only patient's daily travelling and bleeding but also helps them to concentrate fully only on their therapy during that time span. This project will save further joints damage of the patients.

This year under this project on an average 2 therapist doctors have supported for 107 home visits during this period. The total fund spend on this project was about Rs. 53,500.

HELP TO PERSON WITH HEMOPHILIA

- In this year from Apr'2022 to Mar'2023 we have received major donation of Rs. 90,000/- from M/s. Pranav Associates (Mrs. Vaishali Nakashe, Mother of PwH) & Rs. 1,40,000/- from Mr. Devang Shah.
- Remarkable Donations by our Donor: Received donation of Rs. 50,000/- from Mr. R. J. Poonjiaji, Rs. 14,000/- from Mr. Roomy Daruwala, Rs. 45,000/- from Mr. Ashish Kumar, Rs. 10,000/- from Mrs. Lakhbir Kaur, Rs. 5,001/- from Mr. Ankit Shah, Rs. 3,000/- from Mr. Dhanish Kothari, Rs. 3,000/- from Mr. Jayneesh Shah, Rs. 2,000/- from Mr. Rajiv Padhi, Rs. 1,500/- from Mr. Chetan Motiwaras, Rs. 10,000/- from Dr. Sanjivani Diwan, Rs. 10,000/- from Mr. Rubel Lemos, Rs. 5,000/- from Mr. Shivraj More, Rs. 4,000/- from Mrs. Dina Irani, Rs. 5,001/- from Mrs. Kavita Mehta, Rs. 3,000/- from Mr. Salim Bhaldar, Rs. 12,000/- from Mrs. Santosh Mundra, Rs. 10,000/- from Mrs. Shaila Correia Rs. 6,000/- from Ms. Ramadevi Mundhra and Rs. 1,001/- from Mrs. Pratiksha Mishra.

RELIEF OF POVERTY

- HSMC gave monthly Rs. 1,000/- for purchase Grocery Items to 5 PwH below poverty line family. For this spend Approx. Rs. 60,000/- during the period Apr'2022 to Mar'2023.
- We distribute medicine in subsidized cost and sometime free of cost to PwH / CwH who come from their registered chapter in KEM Hospital for treatment. Robinaxol, Texakind, Etoxib(90), Calcirol D3 Sachet. In this FY 2022-23 PwH/CwH took this benefit medicine worth Rs. 4,58,556/-.

USEFUL INFORMATION

KEM HOSPITAL IHTC TIMINGS

Hematology OPD:

Doctor's Name: Dr. Chandrakala.

Address: New Bldg, 1st Floor OPD No: 201. KEM Hospital Parel, Mumbai-400012

Available: Monday & Thursday

Case Paper Time: 8 am To 10 am OPD Time: 9 am to 12 pm.

Hemophilia Day Care Center Address: KEM Hospital, New Building, 11th Floor. Time 9 am to 5 pm

Occupational Therapy OPD:

Doctor's Name: Dr. Kirti Patil

Address: Room No. 4, Ground Floor, CVTC Bldg., KEM Hospital, Parel, Mumbai.

Available on: Monday & Thursday 9 am to 12 pm & 1 pm to 3 pm

Tuesdays, Wednesday, Friday 1 pm to 3 pm & Saturday 9 am to 12 pm. (Phone No. 022-24107562)

Orthopedics Department OPD:

Doctor's Name: Dr. S. S. Mohanty

Address: Ground Floor, KEM Ortho Bldg., Opp. Tata Hospital Parel, Mumbai.

New Patient: Available on Wednesday - Case Paper Time 08.30 am To 10.30 am

Old Patient: Available on Saturday - Case Paper Time 01.30 pm To 03.30 pm

Doctor's Name: Dr. M. M. Desai

Address: Ground Floor OPD No. 404 KEM Ortho Bldg. Opp. Tata Hospital Parel, Mumbai.

New Patient: Available on Monday- Case Paper Time 08.00 am To 10.30 am

Old Patient: Available on Thursday - Case Paper Time 01.30 pm To 03.30 pm

GI Medicine Gastroenterology (HCV) Dept:

Doctor's Name: Dr. Aakash Shukla

Address: KEM Hospital, OPD No. 13, 1st floor, New Bldg., Parel, Mumbai.

New Patient: Available on Wednesday - Case Paper Time 08.30 To 10.30 am

Old Patient: Available on Monday Morning & Friday Afternoon - Case Paper Time 08.30 To 10.30 am

Dental Department:

Doctor's Name: Dr. Nanda Pai.

Address: Old Registration Bldg., 1st floor OPD No. 104 KEM Hospital Parel, Mumbai-400012

Available on Monday To Saturday Case Paper Time 08.00 am To 10.30 am

On Govt. Holidays all Centers will remain close.

USEFUL INFORMATION

Hemophilia Carrier Detection & Prenatal Diagnosis:

Doctor's Name: Dr. Bipin Kulkarni.

Address: New Bldg, 13th Floor, Room No: 1309 KEM Hospital Parel, Mumbai-400012

Available on Monday to Friday. With Prior Appointment Dept. No. 022- 24138518/19

(Govt. Holiday Center will remain close)

OTHER HEMOPHILIA TREATMENT CENTERS & CLINIC

BORIVALI BMT CENTER (Pediatric Hospital):

Doctor's Name: Dr. Mamta Manglani, Dr. Ratna Sharma, Dr. Pranoti Kini, Dr. Amit Jain

Address: CTC, PHO & BMT Center of MCGMCCI Building, Jai Jawan Nagar, Opposite Kanakia Exotica, Behind Suswagath Hotel, Borivali East, Mumbai, Maharashtra 400066

Phone: +91 22 2854 1018 / +91 22 2854 1017

Timing: 24 Hours

K J SOMAIYA HOSPITAL AND RESEARCH CENTER:

Doctor's Name: Dr. Savita Rangarajan (Consultant Hematologist, UK)

Address: CTRU, 3rd Floor, K.J. Somaiya Hospital & Research Center, Somaiya Ayurvihar, Eastern Express Hwy, Sion East, Mumbai, Maharashtra.

Phone: +91 22 5095 4782

Timing: Monday to Saturday 10 am to 5 pm

Doctor's Name: Dr. Shrimati Shetty (Laboratory Hematologist)

Available on: Monday to Friday

Timing: 11 am to 4 pm

With Prior Appointment From Dept. No. +91 22 5095 4700 & Ext. No. 4782

Doctor's Name: Dr. Shweta Bansal (Pediatric Hematologist)

Available on: Monday and Thursday at CTRU Surgeon lab

Timing: 11 am to 1 pm

Phone: +91 22 5095 4782

Doctor's Name: Dr. Shrinath Kshirsagar (Hematologist)

Available on: Only Thursday at Medicine OPD No. 20

Timing: 11 am to 1 pm

Phone: +91 22 5095 4782

Hemophilia Treatment Center, Thane Civil Hospital:

Doctor's Name: Dr. Khandagle, Dr. Megha

Address: Hemophilia Day Care Centre New Thane Civil Hospital Near Mental Hospital Teen Haat Naka Thane (West) Maharashtra

Phone: +91 70392 62238

Timing: Monday to Saturday 10 am to 4 pm

On Govt. Holidays all Centers will remain close.

USEFUL INFORMATION

PRIVATE CLINIC

Dental Clinic

Doctor's Name: Dr. Mehul Mehta

Address: Dr. Bhogilal Bhavan 5th Mamaledar Wadi, Malad (W) Mumbai. 400064

Phone: +91 9820401367

Timing: 10.00 am To 07.30 pm

Homeopathy Clinic:

Doctor's Name: Dr. Hiral S. Bothra.

Address: 6/57 1st Floor, Shree Ganesh Krupa Sahakari Gruha Sanstha, Ekta Nagar, Mahavir Nagar, New Link Road, Opp. Petrol Pump, Kandivali (West) Mumbai-400067.

E-mail: dr.hiralbothra@gmail.com

Mob No: 7738917504

Hemophilia Federation (India)

Address: A-128, Mohammadpur (Behind Bhikaji Cama Place) New Delhi-11006

Phone: 011-45034951 / 45034972 / 41552819

E-mail: ceo@hemophilia.in

Website: www.hemophilia.in

To know about Hemophilia Society all over India, please visit www.hemophilia.in or contact HSMC office.

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Novo Nordisk India Pvt.Ltd.
Reliance Life Science
Roche Pharmaceutical
Save One Life Organization
Takeda Pharmaceuticals
World Federation of Hemophilia

Doctors:

Dr. Akash Shukla	Dr. Nanda Pai
Dr. Bipin Kulkarni	Dr. Nimesh Kulkarni
Dr. Chandrakala S	Dr. Pranoti Kamat
Dr. Devila Sahu	Dr. Pravin Bangar
Dr. Farah Jijina	Dr. Rucha Patil
Dr. K. Ghosh	Dr. Sangita Rawat
Dr. Karuna Nadkarni	Dr. Saurabh Phadke
Dr. Kirti Patil	Dr. Savita Rangarajan
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Hemophilia Society Mumbai (Chapter)

Affiliated to Hemophilia Federation (India)

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