

STRONGER TOGETHER

For Better Hemophilia Treatment



Hemophilia Society Mumbai (Chapter)

32nd Annual Report 2023 - 2024

MESSAGE FROM HSMC



As we conclude another year, I am filled with immense pride and gratitude for the incredible progress our Hemophilia Society has made. Despite the challenges, we have continued our mission to support individuals with hemophilia, ensuring access to essential treatment, raising awareness, and advocating for a better quality of life for all those affected.

This year, our efforts, especially through our Women's and Youth Groups, have gained significant momentum. We have strengthened our relationships with healthcare professionals and government bodies, ensuring that hemophilia remains a priority on the health agenda. Our chapter's advocacy has resulted in key breakthroughs, from securing commitments from health authorities to improving treatment accessibility.

Our partnership with international organizations like SOL and our growing collaborations within the Mumbai chapter highlight our commitment to expanding our reach and impact. I am proud of the work our team has done, and I believe we are on the right path to achieving even greater success in the coming year.

This progress would not have been possible without the dedication of our members, volunteers, and generous supporters. Together, we are making a tangible difference in the lives of people with hemophilia.

Let's continue this journey with renewed energy, knowing that every step we take brings us closer to a world where hemophilia care is accessible to all.

We extend our heartfelt gratitude to the dedicated doctors and staff at the following treating centers: KEM Hospital, Parel; Wadia Children's Hospital, Parel; MCGM CTC Hospital, Borivali; KJ Somaiya Hospital, Chunabhati; and all the Maharashtra HTC Centers. Your unwavering support ensures that we, as hemophilic patients, feel safe and cared for, especially at KEM Hospital, which provides 24/7 care every day of the year.

A special thanks to our generous donors whose financial support plays a crucial role in empowering our hemophilia community. With great pride, we announce that we are now a CSR-compatible registered trust. We invite all businesses and organizations to consider supporting us through their Corporate Social Responsibility initiatives. Your contributions will help us make significant strides in our efforts to support and uplift the hemophilic community. Together, we can make a profound difference!

Thank you for your continued support.

Managing Committee

Hemophilia Society Mumbai (Chapter)

MESSAGE FROM DOCTORS



It is a great honour for me to write this message for one of the country's most active self-help NGOs, which is both run by and dedicated to persons with haemophilia (PWH). Since its inception in 1993, the society has made impressive strides, now supporting over 1,200 PWH and others with bleeding disorders. The organization has effectively voiced the challenges faced by PWH to policymakers. Their collective efforts have led to significant progress in the availability of clotting factor concentrates, organizing camps for inhibitor screening and carrier diagnosis, prenatal counselling, free medication distribution, therapist home visits, rehabilitation, and more. The society also arranges fun, non-academic activities to keep PWH and their families engaged and motivated. With

capable leadership at both the national and local levels, the passionate, creative, and enthusiastic team of office bearers and volunteers always takes on their responsibilities with a positive attitude. I congratulate the society on their noble work and wish them continued success in their efforts to improve the lives of those in the haemophilia community.

Dr. Bipin P. Kulkarni,

Ph.D., MNAMS, CGC

Scientist E / Deputy Director

Head, Department of Haemostasis and Thrombosis

Director, WFH- International Hemophilia Training Centre (IHTC), Mumbai

Associate Professor, Academy of Scientific and Innovative Research (AcSIR)

ICMR- National Institute of Immunohaematology

Parel, Mumbai- 400012.



Greetings from Department of Dentistry, KEM Hospital.

As in previous years, the Department of Dentistry, KEMH continuously strives to treat the dental problems faced by patients with Hemophilia and Allied bleeding disorders. From managing spontaneous oral bleeds, and extracting badly destroyed teeth we have now moved on to restorative procedures like fillings and single-visit root canal treatment thereby giving patients a better quality of life both physically and mentally. We also provide planned aesthetic dental corrections for our hemophilic patients besides handling dental and soft tissue emergencies; to enhance our patients' subjective well-being, life satisfaction, and happiness.

For hemophilic children requiring multiple dental interventions, we offer management under general anesthesia through collaboration between a hematologist and pediatric anesthetist. We are bringing in newer innovative techniques to give our hemophilic patients a healthy dental hygiene. Additionally, we screen hemophilic children whether or not on prophylaxis for oral hygiene, allowing us to diagnose their dental problems at a young age and educate them on maintaining cavity-free oral health for life. I wish the Mumbai chapter the very best for all their future endeavours.

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 2024:

Total 35 new members registered during the year from 1st April 2023 to 31st March 2024. As on 31 March 2024, **Total Registered Members: 949**

Anti Hemophiliac Factor Consumption:

	Factor VIII		Factor IX		FEIBA		Novo 7	
Year	2023-24	2022-23	2023-24	2022-23	2023-24	2022-23	2023-24	2022-23
Total	2,092,07 i.u.	93,840 i.u.	34,600 i.u.	88,760 i.u.	—	4500 i.u.	—	6 mg

Kem Hospital Diagnosis Of Factor Deficiency & Test Report

ICMR- NIIH: Dept. of Haemostasias & 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	—	—	—

Registration No : F - 17067

FUNDS & LIABILITIES	AMOUNT (Rs.)	AMOUNT (Rs.)	PROPERTY & ASSETS	AMOUNT (Rs.)	AMOUNT (Rs.)
TRUST FUNDS OR CORPUS :			Immovable Properties :		
Balance as per last Balance Sheet	7,18,309.50		(Common Schedule "G")		5,17,690.50
Add : Received during the year	-				
Less : Adjustment during the year	-	7,18,309.50	Movable Properties :		
			(Common Schedule "G")		97,705.45
Life Membership Fees					
Opening Balance	17,65,750.00		Investments :		
Add : Additions During the year	67,500.00		Bank Fixed Deposits (Schedule "H")		1,47,98,076.50
Less : Written off as not recoverable	-	18,33,250.00	Accrued Interest on Bank FD's		10,29,972.15
Other Earmarked Funds : (Schedule "E")			AMOUNT RECEIVABLES :		
(Created under the Provision of the the trust deed or scheme or out of the Income)					
a) Fund for Arzawise Therapist - PWH Meeting	1,02,237.84		Loans (Schedule "I")	2,03,100.00	
b) Fund for HCV Treatment	1,29,612.00		Steady Debt Balances	7,078.14	7,95,187.14
c) Nurse Project - India Fund	15,100.00				
d) Screening & Laboratory of PWH - NMO	577.00				
e) Education Fund	1,45,887.00		Advances & Other Deposits (schedule "J") :		
i) Rural Area	-		TDS	2,54,198.05	
ii) Hemophilia Care Centre Fund	24,45,669.00				
iii) Finance Fees	1,56,600.00	40,31,682.84	Advances Others	2,193.00	2,55,381.05
Loans (Secured or Unsecured) :			Cash and Bank Balances :		
From Trustees	-		a) In Current A/c with		
From Others			Bank Balance (Schedule "K")	6,77,311.94	
			b) Cash in hand		
			With the Trustee	5.00	
			With the Manager	847.13	6,18,157.87
Liabilities :					
For Expenses - Schedule "F"	53,100.00				
Members	18,37,102.53				
Amount Set Apart	3,50,000.00	22,40,202.53			
Income & Expenditure Account :					
Balance as per last Balance sheet	79,94,521.20				
Less : Appropriation , if any	Nil				
Add : Surplus/Deficit (As per Income and Expenditure Account)	7,03,184.63	87,87,705.83			
		1,76,13,100.70			1,76,13,100.70

For HEMOPHILIA SOCIETY MUMBAI (CHAPTER)

Printed in Great Britain by the University Press, Cambridge

Date 17th September 2024

PRESIDENT / SECRETARY / TREASURER



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

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

Registration No : E - 17067

INCOME & EXPENDITURE ACCOUNT FOR THE YEAR ENDED 31ST MARCH, 2024

EXPENDITURE	AMOUNT (Rs.)	AMOUNT (Rs.)	INCOME	AMOUNT (Rs.)	AMOUNT (Rs.)
To Expenditure in respect of properties :			(accrued)		
Rates, Taxes, Cesses	-		By Rent		
Repairs & maintenance	-		(realised)		
Salaries	-				
Insurance	-		(accrued)		
Depreciation	-		By Interest		
(by Way of provision of adjustment)	-		(realised)		
Other Expenses	-		(Schedule " C ")		
			On Bank FDR's	8,41,253.00	
			On Loans		
			On GOI Bonds	87,990.62	
			On Bank Account's	49,578.00	
			On Debentures		7,64,821.62
To Establishment Expenses (Schedule "A")		7,67,555.44			
To Remuneration of Trustees			By Dividend		
To Legal Expenses & Professional fees					
To Audit Fees		59,000.00			
To Amount Written off :			By Donations & Contribution Received		
a) Amount Written off	-		(Schedule " D ")		17,30,077.50
b) Loan Scholarship	-				
c) Irrecoverable Rents	-		By Income from other sources		
d) Others Items	-		(in details as far as Possible)		
			- Sponsorship (Schedule " D ")	11,94,082.00	
			- Sale of Scrap		11,94,082.00
To Miscellaneous Expenses			By Amount Recovered		
To Depreciation		75,960.55	a) Provision for Doubtful Debts Reversed		
To Amounts transferred to reserve for Doubtful debts			by Contribution written off earlier now recovered		
To Expenditure on object of trust :					
a) Religious					
b) Educational					
c) Medical Relief	15,43,511.50				
d) Relief of Poverty	2,39,763.00				
e) Other Charitable Objects			By Excess Provision Written Back		
(Schedule " B ")					
		17,83,274.50			
To Surplus Carried over to Balance sheet		7,93,184.63			
		34,78,981.12			34,78,981.12

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

For HEMOPHILIA SOCIETY MUMBAI (CHAPTER)

Shashikant P. Gupta
Partner
Membership No : 031899
Mumbai
Date 17th September 2024



HEMOPHILIA SOCIETY MUMBAI (CHAPTER)

Page
TRUSTEES

PRESIDENT SECRETARY / TREASURER

Pratik L. Mehta

MEETING CARD

Report of Executive Committee Meetings:

9 Executive Committee Meetings held during the period for planning and executing the society's activities. This record from Sep'2023 to Aug'2024.

Name	Designation	Present	Absent
Mr. Paresh Parmar	President	8	1
Mr. Pratik Mehta	Vice President	9	0
Mr. Jigar Kotecha	Hon. Secratory	9	0
Mr. Prasad Shinde	Jt Secratory	6	3
Mrs. Veronica Correia	Treasurer	8	1
Mr. Rupal Panchal	EC Member	0	9
Mr. Krunal Kotecha	EC Member	6	3

Name	Designation	Present	Absent
Mr. Kalpesh Patil	EC Member	3	6
Mr. Mahesh Mundra	EC Member	7	2
Mr. Sunil Jadhav	EC Member	8	1
Mr. Uttamchand Mehta	EC Member	7	2
Mr. Sandeep Kawle	EC Member	6	3
Dr. Anuradha Samant	Women Group Representative	2	7
Mr. Jaynit Jogi	Youth Group Representative	8	1
Mr. Ravi Singh	CSR Head	2	7

AGM of HSMC Last Year:

We held our 31st Annual General Meeting on October 29, 2023, at Krishna Vatika Hall, Goregaon. The event started with lunch at 1 pm, followed by the AGM at 2 pm. Mr. Paresh Parmar invited dignitaries, including Dr. Devila Sahu (Election Officer), Mrs. Indira Nair (Women Group Chairperson, HFI), and others. The dignitaries lit the lamp, and the meeting began with the National Anthem.

Mr. Krunal Kotecha (Vice President) welcomed everyone, and Mr. Paresh Parmar (Hon. Secretary) conducted the meeting. Agendas were discussed and approved, and Dr. Devila Sahu oversaw the election process, announcing the newly elected EC members for 2023-2025. They pledged to work for People with Hemophilia (PwH). The AGM ended with a Vote of Thanks from Mr. Paresh Parmar, followed by snacks and tea. The Women's and Youth Groups also held separate meetings to elect their EC representatives.



AGM of HFI Last Year :

The Annual General Meeting 2023 of HFI is held at Bhopal, Madhya Pradesh on 16th and 17th of September 2023. From Mumbai Chapter Mr. Jigar Kotecha attended the HFI AGM.

ACTIVITY REPORT

Diwali & Founder's Day Celebration

We are pleased to inform you that the Diwali function & Founder's Day organized by the Hemophilia Society Mumbai (Chapter) Youth and Women group on 18th November 2023 at ICMR hall, 13th Floor, KEM, was a resounding success. The event began with a tribute to Late Shri Ashok B. Verma Ji, the founder member of Hemophilia Federation of India, followed by an insightful introductory speech by Mr Kalpesh Patil (EC Member HSMC) Mrs Veronica Correia (EC Member & Women Chair Person HSMC) and Mr Prasad Shinde (EC Member HSMC) coordinated various fun games for women and children, with prizes awarded to the winners. Women President HFI & HSMC Senior Member Ms Indira Nair ji given some useful suggestions & Diwali wishes to all program attendees, Mr Jaynit Jogi (Youth President – HSMC), Mrs Anuradha Samant (Women President - HSMC) & EC Member of HSMC distributed Diwali faral (Nasta), and a lively Diwali pataka was played on the ground by all attendees at HSMC Office Ground After expressing gratitude, snacks were served, and the program was attended by more than 50 peoples. The celebration was thoroughly enjoyed by all members, including PwH children.



Christmas Celebration

Youth along with Women group of Hemophilia Society, Mumbai Chapter celebrated Christmas with PwH with their parents on 23rd December 2023 at ICMR hall, KEM. We were Happy to welcome Mrs Lakhbir Kaur, our patron member, UK, Mr Ramu Gadkar, VP HFI, Mrs Indira Nair, WG chair person HFI. Mr Jigar Kotecha, Secretary, HSMC were also present.



Mrs Lakhbir Kaur who have come to India for her charitable work, had visited KEM PwH wards, and also Thalesimia patients and distributed fruits at 10th floor and 11th floor wards including Nurses and Aayas.

At the outset Mr Ramuji welcomed all members and were glad to see everyone gathered with a great enthusiasm. Mrs Veronica Correia, Treasurer and WG coordinator, organised singing of Christmas carol singing and portrayed a girl as Mother Mary and a boy as Joseph. The singing was followed with Santa distributing gifts to the children. Various fun games were played and prizes were distributed. Mr Jaynit, youth group leader, coordinated with various games.

Mrs Lakhbir Kaur gave inspirational talk on self reliant to all women present. Mrs Indira Nair said women should participate in various competitions being held time to time. The program ended with wishing everyone Merry Christmas and delicious snacks were served. All in all it was fun and frolic and everyone enjoyed the program.

ACTIVITY REPORT

Mumbai & Thane Chapter Joint Camp at Khandala

We are pleased to announce that the Hemophilia Society Mumbai Chapter & Thane Chapter organized a joint camp for Persons with Hemophilia (PwH) from December 29th to December 31st, 2023, at Khandala. Approx. 50 PwH participated in the camp, which featured various activities.

The joint camp by Mumbai and Thane Chapters, generously sponsored by Mrs. Lakhbir Kaur, was a celebration of unity for our hemophilia patients. The well-planned activities promoted physical and emotional well-being, resulting in a wonderful and rejuvenating experience. Such events have a positive impact, boosting confidence and overcoming negativity. We urge HFI/RCC to consider organizing larger-scale camps regularly for enhanced patient outcomes.



SOL Fund Distribution

On January 13, 2024, a meeting was successfully conducted at the HSMC office with SOL beneficiary, HSMC Treasurer Mrs. Veronica Correia, EC member Mr. Sunil Jadhav, and staff Sheetal & Ravindra. Funds were distributed to all 32 SOL Sponsorship beneficiaries, and the meeting concluded with delicious snacks.



ACTIVITY REPORT

WGBD Clinic Workshop

Exciting Update from WGBD Clinic Workshop at ICMR, KEM, Mumbai on 8th Jan 2024!

We're thrilled to share the exciting news that the esteemed delegates from the UK Royal London Hospital, Dr. Suthesh Sivapalaratnam & Dr. Mandeep Kaler, visited KEM Hospital, Mumbai, on January 8th, 2024. Accompanied by Dr. Devila Sahu, Mr. Prem Alva, Mr. Harshal Kale, Mr. Ramu Gadkar, and Ms. Indira Nair, they focused on the WGBD clinic project for Women Bleeder patients in Mumbai and Thane.



The day kicked off with a meeting at ICMR hall, 13th floor, where they engaged with distinguished individuals, including Dr. Chandrakala, Dr. Manisha, Dr. Bipin Kulkarni, Dr. Rucha Patil, Dr. Nanda Pai, and Dr. Kirti.

The workshop on the 11th floor clinic, aimed at addressing Women with VWD Factor deficiency and bleeding disorders, began at 12:45. The guests were presented with New Year greeting cards crafted by our Women's group during the Christmas Greeting card competition.



Mr. Harshal Kale introduced the guests, Mr. Prem Alva welcomed them & briefed about WGBD Workshop, and Dr. Chandrakala highlighted the importance of the WGBD Clinic. Dr. Bipin Kulkarni emphasized the need for the clinic, and Mr. Ramu Gadkar encouraged women to support this initiative.

Dr. Suthesh Sivapalaratnam & Dr. Mandeep Kaler, Chief Guests, shared insights on how openness about women's health is embraced in the UK. They urged Indian women to openly discuss their concerns with the Hematology Dept at KEM for guidance and

care.

Women from Mumbai and Thane chapters shared their experiences, considering Dr. Chandrakala as a guardian angel. A Q&A session followed, addressing queries from VWD women with positive responses from the guests.

Mrs. Indira Nair conveyed the Vote of thanks, and Mrs. Veronica Correia has hoisted the program ,

Mrs. Veronica Correia, Jigar Kotecha & Mumbai Chapter Staff looked after this program from preparation till the end. 37 VwD Women actively participated in free interactions.

Hemophilia Society Mumbai Chapter happily hosted this event. Veronica Correia, Anuradha Samant & Sunil Jadhav, along with staff members Ravindra and Shital, were present to warmly welcome all Guests, Doctors, Thane Chapter EC Members & concluded the program with a delicious lunch thereafter.

A heartfelt thanks to all VWD women, staff, and supporters for making this workshop a success!

ACTIVITY REPORT

BMD & Eye Check-up Camp

Hemophilia Society, Mumbai (Chapter) proudly conducted its first-ever BMD Test & Eye Check-Up Camp in collaboration with Platinum Hospital at Somaiya Hospital on February 3, 2024. Dr. Savita Rangarajan, Director and Hematologist at Somaiya Hospital, kicked off the program with insights on BMD and the challenges faced by Hemophilia patients.

Mr. Jigar Kotecha emphasized the importance of such tests for maintaining good health. The event witnessed a delicious lunch at 01:30 pm, and the BMD test and eye check-up continued until 04:30 pm, benefiting 126 participants.

A special shoutout to Ms. Veronica Correia, instrumental in convincing Platinum Hospital for a nominal convenience fee, and Mr. Sunil Jadhav, who secured the venue at Somaiya Hospital. Kudos to Shital, Ravi and EC members for making this event unforgettable!

This achievement, guided by Dr. Chandrakala, marks a milestone for the Hemophilia Community Mumbai. We plan to organize more such Medical Camps in the near future. A big thank you to our associated doctors, donors, ex-senior EC members, Capital Hospital (Mr. Santosh Shelar & Team), and, most importantly, our Hemophiliac Patients.



Haldi Kumkum Celebration

On February 3rd, 2024, a joyous Haldi Kumkum celebration unfolded at the same venue where a Medical Camp took place. Mrs. Veronica Correia warmly welcomed the ladies, followed by the traditional Haldi Kumkum ceremony led by Ms. Anuradha and Sheetal. Ms. Veronica orchestrated delightful games, and everyone danced to great tunes. Tasty snacks were served, and gifts were joyfully shared among the 45 enthusiastic participants. A heartfelt thanks to Mr. Sunil for his efforts in booking the venue and arranging snacks and lunch. Special appreciation to Mrs Veronica and the dedicated women group members for their wonderful volunteering. Gratitude to our tireless staff, Ravindra and Sheetal, for contributing to the success of both events.



ACTIVITY REPORT

Hemophilia Awareness

Arya Vidya Mandir school at Bandra Kurla Complex had organised "Arya Prabha Diwas" on 12th February'2024 for this they invited our CwH between 8 to 12 age group. Our 17 children participated and their parents total 30 people participated in the event. Also HSMC staff Ravindra attended the event. 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.



Advocacy Meeting

Exciting News Alert! On February 13, 2024, a pivotal Joint Meeting took place at the Divyang Karyalaya, Mantralaya Mumbai, bringing together some incredible individuals and organizations for a crucial cause!



Participants:

Shri Bachu Kadu Ji, MLS Shivsena
Dr. Vijay Bawiskar Ji, DHS
Dr. Mahendra Kendre, DHS

Key Persons of Hemophilia Maharashtra Chapters

Dr. Vyenketesh Parlikar, Advocacy Head of Maharashtra HFI
Mr Ramu Gadkar, VPD HFI

Under the inspiring guidance of Dr. Vyenketesh Parlikar, we united forces to address the pressing need for continued factor supply and advocating for prophylaxis for our beloved hemophilia patients!

Home Chapter Support:

As the proud Home Chapter of Mumbai, we are thrilled to lend our wholehearted support for all necessary paperwork and supporting documents.

Coordination at Its Best:

A huge shoutout to Mr. Jigar Kotecha for his outstanding coordination efforts with HFI and DHS, ensuring smooth sailing for this momentous gathering!

Representation:

Representing the Mumbai Chapter, Mr. Pratik Mehta and Mr. Sunil Jadhav, alongside other dedicated Keypersons from various chapters, made their impactful presence felt!

This isn't just a meeting; it's a powerful statement of solidarity and commitment to the better health and well-being of our hemophilia community! Let's keep pushing forward, together!

ACTIVITY REPORT

International Women's Day Celebration

Hemophilia Society Mumbai Chapter Women's group, celebrated the International Women's day on Friday, 15th March 2024 at 11th Floor, KEM Hospital, with all the Doctors and Nursing staff hosted by Mrs Veronica Correia.

The program was graced by Dr Chandrakala Madam, HOD, Hematology Department, KEM, by cutting the cake with the Hemophiliac children. As a token of love, we honoured all Doctors, nurses and their staff with a rose flower and a memento. We thanked all the Doctors, nurses and their staff for their selfless service round the clock to our Hemophilia patients. Dr Chandrakala Madam and their staff reciprocated our gesture with the happy note and support.



The Doctors along with Dr Chandrakala Madam present were:

Dr Nanda Pai, HOD, Dental Department, KEM,
Dr. Kirti Patil (clinical occupational Therapist KEM)
Dr. Jyoti (hematology Resident Dr. KEM)
Dr. Aishwarya (hematology Resident Dr. KEM)
Dr. Priyanka (hematology Resident Dr. KEM)
Dr. Rucha Patil (scientist ICMR) and all the Nursing staff.



EC members present were Mrs Veronica Correia, Treasurer and Mr Jaynit, Youth Group Leader along with Women group. The function was ended with serving the snacks and the sweet memories. On Saturday 16th March, a group of Women were gathered at KJ Somaiya Hospital at 2 pm for the session on Human Rights and Psychosocial by Ms Radhika Verale and Ms Jyoti and the speakers were invited by Mrs Veronica Correia.

The session started with the Lunch. At the outset, we welcomed all Women and the guests speakers. Ms Radikha in her session, stressed on human rights and said Women while doing her day today routine if she finds anything wrong or injustice done, it should be taken up with the positive attitude and Spirit and not with the fighting note. The session went off very well. Ms Indira Nair, chair person, Women group, HFI were also present. She inspired the Women group to come forward and take initiatives with her Psychosocial talk. Mrs Veronica Correia also inspired all Women present and said do not fear for anything, be bold and you will achieve everything. The meeting ended with the Vote of thanks and sweet distribution.

ACTIVITY REPORT

Factor Distribution & Physio Session

On March 16th, 2024, the Hemophilia Society Mumbai Youth Team organized a fantastic Physiotherapy Session led by Dr. Prachi Sarvaiya. With 100 patients in attendance, Dr. Sarvaiya emphasized the crucial role of exercise in managing Hemophilia. She taught essential exercises and held a productive Q&A session, empowering all attendees.

Following the enlightening session, Factor Distribution took place, benefitting 60 critical Hemophiliacs dealing with recurring bleed issues. 25 Factor 8 patients and 35 Factor 9 patients received much-needed support, improving their quality of life.



Special thanks to Somaiya for providing the venue, facilitated by Sunil Jadhav. Kudos to Ms. Veronica Ji for mobilizing the women's group, and a big shoutout to Mr. Jaynit Jogi, the Youth Leader, and his dedicated team, along with the support staff Ravindra & Sheetal, for their hard work in making this event a success.

Gratitude to Mr. Pratik Mehta for securing Factor and lunch support from Intas Foundation, making this event possible. This program exemplifies the incredible teamwork of the Mumbai Chapter, showcasing everyone's dedication to our Hemophilic Community.

WFH Visit at KEM Hospital

Happy to share the exciting visit by World Federation Hemophilia (WFH) delegates along with Mr. President-HFI Prem Ji, our beloved Mr. Ramuji Gadkar, Dr. Cesil Ross, and Harshal Kale, Asia Head WFH, at Kem Hospital, Parel Mumbai. They met with Children as well Elders with Hemophilia at Kem to understanding how there humanitarian support is necessary for all Hemophiliacs, For that they came on 27/3 to 28/3/2024.



The WFH team, including Dr. Assad Haffar and humanitarian aid donors from pharma companies like Sanofi, Belief, and SOBI, visited ICMR, IHTC Day Care Centre Hospital, and were warmly welcomed in the Maharashtrian way.

During their visit, they met with HOD of Hematology Dr. Chandrakala, Dr. Bipin Kulkarni & the ICMR Department Team, Orthopaedic Dr. Mohanty, Occupational Therapist Dr. Kirti Patil, Dental Dr. Nanda Pai, and Nuclear Departments



ACTIVITY REPORT

Dr. Swetal Pawar. They also had group meeting and then video shoots capturing the essence of their interactions.

Then they came to IHTC Centre, Veronica Ji introduced our guests to all program attendees (Hemophiliacs), welcoming them with flowers & ball pen sets as a gesture of respect and love. WFH delegates interacted with Pwh & Cwh with the help of translators Jigar Kotecha & Veronica Ji, They celebrated Premji's (President HFI) birthday, followed by a delightful meal.

Our Brother Chapter Thane Team EC joined in welcoming the guests, enhancing the program's warmth and inclusivity.

The next day, the WFH Delegates explored departments where Hemophiliacs receive treatment, accompanied by Harshal Kale Ji, Ramuji, our Youth Team, Veronica Ji, Jaynit, & Ravindra. They also visited a Hemophiliac's home, experiencing a heartwarming welcome.



The ultimate goal of this visit was to understand how Hemophiliacs in India navigate various challenges. We're grateful to HFI for acknowledging the importance of India's top treatment centers and striving to update all IHTC & HTC centers with WFH's support in future.

Special thanks to Mr. Prem Ji, Dr. Cesil Ross, Mr. Ramu Gadkarji, and Harshal Kale for their trust and collaboration, making this two-day program a success. We extend our gratitude to Dr. Chandrakala Ji, Dr. Bipin Kulkarni Ji, and all doctors at KEM Hospital for their invaluable time during the WFH Delegates visit. Kudos to our Mumbai Chapter Youth Team, dedicated staff Ravindra & Sheetal, for their fantastic work, ensuring our guests left with smiles and happy memories. Mumbai Chapter is committed to organizing more programs to support our Hemophiliac community. Together, we make a difference!

World Hemophilia Day

Save the Date: April 21st!

Join us as we commemorate World Hemophilia Day at the MLT Auditorium, KEM Hospital, hosted by the Hemophilia Society Mumbai Chapter. Also, this month we spread hemophilia awareness via News paper. Here's a glimpse of what we have in store:

Kick-off with a hearty breakfast and registration. Singing of the National Anthem, lighting of the lamp, and a Ganesh Vandana invocation to set the tone.

Honoring SSC, HSC, undergraduate, and postgraduate students, along with our esteemed doctors, guests, and supporters. With the help of our supporters, we distributed Crepe Bandages, T-shirts, and chocolates to our patients, spreading warmth and encouragement.

ACTIVITY REPORT

Engage in a patient education program led by Dr. Savita Rangarajan, Dr. Kanjaksha Ghosh, and Dr. Mahadeo Garale, offering invaluable guidance. Personal anecdotes shared by Mr. Saurabh Nalamwar (West Region Rcs) adding a special touch to the event. Dr. Shraddha Kamble, Dr. Rameshwar Tangade, Dr. Shama Sidiki, Dr. Dhvani Shah, Dr. Yashwant Waghmare, Dr. Karan Jain, Dr. Ridham Shah, and Dr. Sunit Malvankar led sessions on joint evaluation for hemophilic patients. Occupational therapists conducted sessions on joint evaluation for hemophilic patients.

Heartfelt World Hemophilia Day wishes from Dr. Chandrakala S and Dr. Kale, spreading love and positivity. Fun-filled activities including balloon flying, laughter yoga session by Dr. Ashok Thakare, and an entertaining show for all ages.

Wrapping up with a heartfelt vote of thanks and a scrumptious lunch, fostering a strong sense of community and support. Let's come together to celebrate, educate, and support each other on this special day!



WFH 2024 World Congress, 22.04.2024:

Mrs. Veronica Correia got an opportunity to participate in WFH Congress held at IIFA, Madrid, Spain in April 2024. She was privileged to be honoured with WFH stole by WFH President Mr. Cesar Garrido. This was the great achievement for her.



ACTIVITY REPORT

SOL Documents Submission Meeting

As per the guidelines of SOL Team, all SOL beneficiaries are required to submit documents/bills to receive the Scholarship cheques. Accordingly, on 21st June 2024, a meeting was conveyed with all parents of SOL beneficiaries, by Ms Veronica Correia, SOL coordinator at our Hemophilia Society Mumbai Chapter Office for discussion on submission of documents / receipts to receive SOL Scholarship cheques. She informed everyone that original expenditure receipts like monthly groceries, stationery, School / College fees, uniforms, shoes, tuition fees receipt, monthly gas bill, electricity bills etc. required to be submitted in a folder to HSMC Society Office to enable us to issue the cheques. It was also informed that such bills for the period Jan 24 to July 24, can be provided.



We have total 32 SOL beneficiaries out of which almost 25 parents attended the meeting. The meeting ended with the serving of light snacks & Tea.

Doctors Day

On behalf of HSMC Mr. Paresh Parmar, Sunil jadhav, Prasad Shinde celebrated Doctor's day With Dr. Shrimati Shetty (Scientist, Lab Head), Dr. Shrinath Kshirsagar (Consult Hematologist), Dr. Shruti Dabhale (Hematologist & Hemat Onchologist) and CTRU staff at Somaiya Hospital on 1st July 2024.

Mr. Jigar Kotecha, Mr. Pratik Mehta, Ravi Singh along with staff celebrated Doctor's Day with Dr Chandrakala Chhannavar (Hematologist), Dr. Nanda Pai (HOD, Dental Dept.), Dr. Kirti Patil (Occupational Therapist), Dr. Bipin Kulkarni (Scientist E, Department of Haemostasis and Thrombosis Director, ICMR- NIIH), Dr. Richa Patil (Scientist C, Department of Haemostasis and Thrombosis, ICMR- NIIH) at KEM Hospital on 3rd July 2024. There are no words in which we can thank you for being such a generous human and the best doctor.... You are truly a God for patients with the magical powers to treat them. Best wishes from the entire EC and hemophilia community to you on National Doctor's Day.



ACTIVITY REPORT

Inhibitor Screening, Update Of Mjpjay Government Scheme Along With Celebration Of 40 Years Of Hemophilia Federation Of India

Today, on 27/7/2024, with the help of Dr. Savita Rangrajan and Team of Somaiya Hospital HTC, HEMOPHILIA SOCIETY MUMBAI CHAPTER organized an Inhibitor Test Screening Camp to educate patients about the benefits of the Government Scheme MJPJAY.

Dr. Savita Rangrajan warmly welcomed all patients and highlighted that any MAHARASHTRA resident with a Ration Card & Aadhar Card can now enroll in the newly introduced MJPJAY Scheme. She emphasized our commitment to assisting all patients and discussed future plans for Gene Therapy Trials. Dr. Shrutika elaborated on how patients can enroll at Somaiya Hospital and addressed their queries on MJPJAY Scheme.

Following the informative session, Inhibitor Screening tests were conducted, marking an important step in healthcare. Additionally, we celebrated the 40th Anniversary of the Hemophilia Federation of India with our patients and healthcare professionals, underscoring our journey and achievements. Veronica ji led a special Women's Meet where she briefed Mumbai Chapter's women about various Government Schemes like Ladki Bahin, and MJPJAY.

The program concluded with a delightful lunch, fostering community spirit and awareness.



Women & Youth Group Anniversary Celebration

On 22nd August 2024, Hemophilia Society, Mumbai Chapter celebrated Woman's group and Youth group Anniversary day at our Society Office. On this occasion, we distributed groceries to 8 families. Ms Veronica Correia, Treasurer and Women's group Representative gave phycho Socio talk to all ladies and encouraged them to do some work as a self reliant and not to sit idle. She also said, if any help is required like micro enterprises, they can approach us so that we can try to help. From youth group, Jaynit Jogi, Youth representative attended the meeting.



Almost 15-20 women and youth attended the meeting. The Meeting ended with the snacks.

ACTIVITY REPORT

Annual Women Group Meeting at Ratnagiri

Women's Group Meeting of the West Region, held at Ratnagiri, Maharashtra on 31st August and 1st September 2024.

Day 1:

The meeting began with the dignitaries lighting the lamp, followed by the singing of the National Anthem. A minute of silence was observed in memory of hemophilia patients who lost their lives. The dignitaries, including Ramu ji, Balshiram ji, Vichare ji, Saurabh ji, and Indira ji, gave their presentations. There was a medical session conducted by Dr. Sharada Shanbhag. Artificial gajara (गजरा) was distributed on behalf of the Pune Chapter. The Ratnagiri Chapter organized the Mangala Gaur program, and there was a solo performance by Dhanashree Latte as Jijamata from the Kolhapur Chapter.



Day 2:

During the meeting, Mrs. Veronica Correia was unanimously elected as the Regional Coordinator, and Mrs. Geeta Gadkar was elected as the Assistant Regional Coordinator for the Women's Group – West.

We extend our warmest congratulations and best wishes to both!

Advocacy Meeting

Hemophilia Society Mumbai Chapter: Action Plan Meeting Summary.

Date: September 20, 2024 (Friday)

Location: Society Office & DHS Mumbai.

On September 20, the Women's and Youth Groups of the Hemophilia Society Mumbai Chapter came together to create an action plan for the year. Under the leadership of Mr. Jigar Kotecha, Secretary of HSMC, we took significant steps in our advocacy efforts.

Advocacy Action:

In the afternoon, members visited the Directorate of Health Services to address critical questions regarding hemophilia treatment accessibility. Our banners highlighted key issues:

- "Why is sufficient factor not available?"
- "Equal distribution of factors!"
- "Health Department, let's raise awareness!"
- "Why are CD/PND initiatives not organized?"
- "Insufficient medicines provided!"

Though Dr. Kendre was initially unavailable, we patiently waited until 5:45 PM for a constructive meeting.

ACTIVITY REPORT

Meeting Outcomes:

During the meeting, Dr. Kendre expressed his commitment to tackling these issues and suggested:

- Approaching higher authorities for increased hemophilia treatment budgets.
- Collaborating with pharmaceutical companies for timely factor releases.

The meeting ended on a hopeful note, and we are optimistic about achieving tangible improvements!

Key Participants:

Mrs. Veronica Correia: Newly appointed Western Region Women's Coordinator, who initiated the advocacy action plan.

Indira Nair Ji & Veronica Correia Ji: Explained to Mumbai Youth & Women Group Volunteers how to present our needs effectively at the Directorate.

Miss Sheetal Ghorpade, Ravindra More, and Jaynit Jogi (Youth President): Active volunteers who delivered a fantastic presentation.

We look forward to making meaningful progress in our advocacy efforts!



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 \$11,281.67 (Rs. 9,48,352/- Approx). This help means a lot to Hemophiliacs which was used for various needs like education, food, medicine, and lifestyle improvement.

HELP TO PERSON WITH HEMOPHILIA

In this year from Apr'2023 to Mar'2024 we have received major donation of Rs. 1,20,000/- from Mr. Devang Shah.

Remarkable Donations by our Donor: Received donation of Rs. 50,000/- from Mr. Aniket Diwan, Rs. 25,000/- from Ms. Nandini Nadkarni, Rs. 25,000/- from Mr. Satish Gujran, Rs. 18,000/- from Mr. Jayneesh Shah, Rs. 15,000/- from Mr. R. J. Poonjiagi, Rs. 15,000/- from Mr. Nariman Jahangir Poonjiagi, Rs. 15,000/- from Mr. Roomy Daruwala, Rs. 10,000/- from Mr. Jatin Diwan, Rs. 7,500/- from Pranav Associates, Rs. 7,000/- from Mrs. Sakina Rangwala, Rs. 5,000/- from Mrs. Nazia Rangrej, Rs. 2,000/- from Mr. Dhanish Kothari, Rs. 5,000/- from Mrs. Dina Irani, Rs. 10,000/- from Mrs. Shaila Correia, Rs. 5,000/- from Mr. Vijay Correia 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'2023 to Mar'2024.
- ✳ 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 2023-24 PwH/CwH took this benefit medicine worth Rs. 3,55,067/-.
- ✳ We distributed food coupons (Lunch & Dinner) worth Rs. 1,36,000/- to patients admitted to KEM Hospital during the period from April 2023 to March 2024.

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
(Govt. Holiday Center will remain close)

Occupational Therapy OPD:

Doctor's Name: Dr. Karuna Nadkarni (HOD)

Address: 1st Floor Room No. 412 KEM Ortho Bldg., Opp. Tata Hospital Parel Mumbai. 400012

Available on: Monday To Friday 09 am to 4 pm & Saturday 09 am to 12 pm

With Prior Appointment From Dept. No. 022-24107044 (Govt. Holiday Center will remain close)

Doctor's Name: Dr. Kirti Patil.

Address: C.V.T.C. Bldg. Room No.4 Ground Floor Opp Old KEM hospital Gate No. 3 Parel Mumbai. 400012

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. (Govt. Holiday Center will remain close)

Orthopedics Department OPD Timings:

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 08.00 am To 10.30 am

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

(Govt. Holiday Center will remain close)

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

(Govt. Holiday Center will remain close)

GI Medicine Gastroenterology (HCV) Dept OPD Timings: :

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 & Saturday Afternoon OPD 01.30 pm To 03.30 - Case Paper Time 08.30 am To 10.30 am

(Govt. Holiday Center will remain close)

USEFUL INFORMATION

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

(Govt. Holiday Center will remain close)

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 3530 6589/6587

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 3530 6590

Doctor's Name: Dr. Shruti Dabhade (Junior Consultant)

Available on: Monday and Thursday at CTRU Surgeon lab

Timing: 11 am to 1 pm

Phone: +91 22 3530 6589/6587

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 3530 6589/6587

USEFUL INFORMATION

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
(Govt. Holiday Center will remain close)

PRIVATE CLINIC

Dental Clinic

Doctor's Name: Dr. Mehul Mehta

Location: Malad (W) Mumbai

Phone: +91 9820401367

Homeopathy Clinic:

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

Location: Kandivali (W) Mumbai

Mob No. +91 7738917504

ACKNOWLEDGMENTS

Institutions / Trust:

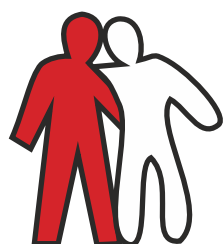
Save One Life Organization
Novo Nordisk Hemophilia Foundation
Novo Nordisk India Pvt.Ltd.
Hemophilia Federation India
Roche Products (India) Pvt. Ltd.
State Blood Transfusion Council
Tata Mumbai Marathon
World Federation of Hemophilia
Indian Council of Medical Research
Laureen Kelly Communication (USA)
N. M. Wadia Trust
Takeda Pharmaceuticals
Shri Sidhivinayak Mandir Trust
Dorabji Tata Trust

Doctors:

Dr. Chandrakala. S	Dr. Karuna Nadkarni
Dr. Akash Shukla	Dr. Kirti Patil
Dr. Savita Rangarajan	Dr. Mamta Manglani
Dr. Shrimati Shetty	Dr. Manisha Madkaikar
Dr. Pranoti Kamat	Dr. Mehul Mehta
Dr. Bipin Kulkarni	Dr. MM Desai
Dr. Rucha Patil	Dr. Nanda Pai
Dr. Shrinath Kshirsagar	Dr. Sangita Rawat
Dr. Shruti Dabhade	Dr. Pravin Bangar
Dr. Devila Sahu	Dr. SS Mohanty
Dr. Farah Jijina	Dr. Sangeeta Mudaliar
Dr. Kanjaksha Ghosh	Dr. Sujata Saunik
Dr. Saurabh Phadke	

Individuals:

Devang Shah	Shaila Correia	Vaishali Nakashe	Sakina Rangwala
Aniket Diwan	Vijay Correia	R. J. Poonjiaji	Nazia Rangrej
Jatin Diwan	Dhanish Kothari	Nariman Jahangir	Dina Irani
Nandini Nadkarni	Roomy Daruwala	Poonjiaji	Pratiksha Mishra
		Jayneesh Shah	Satish Gujran



Hemophilia Society Mumbai (Chapter)

Affiliated to Hemophilia Federation (India)

Registered under societies act, XXI of 1960. No. 752/1994 of GBBSD of 10/08/1994. Registered with Charity Commissioner as Public Charitable Trust Reg. No. F17067 Dt. 24/01/1995. Exempted under IT Act 1961 vide No. AAATH2665QF20215/AY 2022-23 to AY 2026-27.

Admin Office: 205, Sai Apt, 64-B, Swarajya Bhavan CHS., Bhagwan Rao Parelkar Marg, Parel Village, Mumbai - 400012. **Phone:** +91-96533 24634 +91-91376 36241. **E-mail:** mumbai@hemophilia.in
Website: www.hemophiliamumbai.in

Designed by: www.DigitalArts.co.in | +91-9821174260