

Caring, Committed, Connected...



One Country, One Treatment.



Hemophilia Society Mumbai (Chapter)

28th Annual Report 2019 - 2020

MESSAGE FROM PRESIDENT



Greetings To All My Brothers & Sisters,

I hope you all are in pink of health by grace of God. This is my first ever message as president of HSMC. Everybody knows that we are passing through very difficult time since one year and in spite of desire we are unable to do any program / activity due to COVID19.

I am thankful to God for not losing our PwH/CwH due to COVID19. We did special arrangement for factor availability at six different places during pandemic looking to need of our PwH/CwH because they were unable to travel due to lockdown.

During pandemic our dedicated doctors, our E.C. members and staff had given their full support. We got support from WFH through HFI for F-VIII, F-IX, FEIBA and NOVO SEVEN etc. Our many PwH/CwH are getting financial support under SOL scheme through HFI. Our some members are getting educational and higher educational support also from SOL through HFI.

HSMC is thankful to HFI for their great help which changed the life of our PwH/CwH. One more thing I would like to share with you that our many CwH are under prophylaxis. Many PwH are under trial and are doing well. Over and above we are going to register our PwH for upcoming gene therapy trial which will bring revolution in life of PwH.

With the help of Dr Mamta Manglani, we have designated Borivali BMT Center as a HTC for our CwH below 15 years of age and along with KEM hospital we are trying to designate Somaiya hospital as our another HTC so that our members have choice. With the support of Doctors, Donors and E.C. members I am sure that we will achieve our new goal – **One Country, One Treatment.**

Kishore Kotecha

President

MESSAGE FROM VICE PRESIDENT



During this Covid period I am thankful to God who gave me Inspiration & Strength for helping my PwH & Non PwH brothers & sisters.

Last year was tough for all of us, but me & my HSMC Team tried to help as much as possible to all PwH who were in need. It became possible because of all Doctors from various hospitals helped us time to time during this pandemic period, for which I thank KEM Hospital, Dr Chandrakala & her entire team, Borivali BMT Center Dr Mamta Manglani and her team, Thane Civil Hospital Dr Khandale & his team, Somaiya Hospital Dr Savita & her team & also thankful to my HFI management and HFI President Mr. Mukesh Garodia, RCC Ramu Gadkar, HSMC EC and our staff Ms. Megha and Ms. Sheetal.

Thank you for believing in me.

Ajay Palande

Vice President

MESSAGE FROM DOCTORS



Dear Friends,

This unprecedented pandemic has put us in a very awkward situation. We are unable to meet face to face to share our personal and physical problems. But simultaneously it has made us stronger day by day. Now at this stage we have learnt how to accept it and know what we can't change. Let's change what we can and focus on what we can gain out of it. Recently we attended WFH meeting on a virtual platform, a new experience of a new beginning! We learnt another WFH (Work from Home) in this situation. This will help us to reduce our travel time, expenses, prevent traffic snarls and ample time to work relaxly and enough of time to rejoice! This will prevent lot of bleeding episodes as well!!

Once again, I request to sincerely follow up in your treatment schedule and leave no stone unturned to lead a normal life in your future endeavours and simultaneously giving us enough opportunity to learn how to be better off in our approach to PwHs.

Stay Safe! Stay Healthy!!

Dr. Shubhranshu S. Mohanty,
*Professor & Unit Head in Orthopaedics,
KEM Hospital, Mumbai, India.*



It gives immense pleasure to see the HSMC in its 29th year and working for the cause with a dedicated team.

HSMC has supported us in spreading the perspective on hemophilia treatment and future therapies.

We have been able to start international clinical trials which are phase II studies especially for patients with inhibitors. The results has made drastic improvement in the life patients.

As we move in the future I would like to share that we are in the process of screening sero prevalence study for Gene therapy and the look at the first Made in India Gene therapy program for both Hemophilia A and B.

We look forward to continue co-ordination with HSMC stakeholders and wishing them all the best and welcoming Gene therapy together.

Dr. Savita Rangarajan
MBBS, MD, FRCP, FRCPath

QUICK UPDATES

Membership as on 31 March 2020:

Total 17 new members registered during the year from 1st April 2019 to 31st March 2020. As on 31 March 2020, our final membership details are as follow: **Total Registered Members: 855**

Anti Hemophiliac Factor Consumption:

Year	Factor VIII		Factor IX		FEIBA		Novo 7	
	2019-20	2018-19	2019-20	2018-19	2019-20	2018-19	2019-20	2018-19
Paid	66940 i.u.	56396 i.u.	36,000 i.u.	45,000 i.u.	4,000 i.u.	29,000 i.u.	—	—
Donated	115670 i.u.	40250 i.u.	140040 i.u.	1,83,880 i.u.	—	—	—	10 mg
Total	182610 i.u.	96646 i.u.	176040 i.u.	2,28,880 i.u.	4,000 i.u.	29,000 i.u.	10 mg	10 mg

Summary of Financials:

Summary of Balance Sheet	Year 2019-20	Year 2018-19	Summary of Profit & Loss	Year 2019-20	2018-19
	Rs. In Lacs	Rs. In Lacs		Rs. In Lacs	Rs. In Lacs
Trust Funds and Other Funds	134.11	128.87	Gross Income & Closing Stock	40.95	59.68
Fixed Assets	9.59	10.78	Total Expenditure & Opening Stock	35.64	56.97
Investments	127.13	110.49	Surplus	5.31	2.71

Diagnosis & Test done at IIH, KEM Hospital:

Factor Assay and Inhibitor Screening done for 1087 persons with bleeding disorder, out of which the data of PWH is presented here.

	Factor VIII	Factor IX	vWD	Rare Factor
Severe	86	24	—	23
Moderate	39	14	—	8
Mild	32	12	—	9
Inhibitor Positive	68	1	—	1
Other	—	—	49	—

Carrier Detection in Hemophilia A and B:

In the current year 96 females (73 Hemophilia A, 23 Hemophilia B females) were referred for the detection of carrier status. 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, NGS and MLPA.

45 females were found to be carriers whereas 51 females were non carriers.

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

In the current year, total 73 females were referred to us for first trimester antenatal diagnosis of Hemophilia A, B, VWD, Afibrinogenemia, FVII, FXIII and other bleeding disorders. 60 females belonging to Hemophilia A families and 11 females belonging to Hemophilia B families were referred in the first trimester for prenatal diagnosis.

55 fetuses were found to be unaffected whereas 16 were affected. Methods used for analysis were same as that used for carrier detection.

QUICK UPDATES

Report of Executive Committee Meetings:

9 executive committee meetings held during the period for the planning and executing the society's activities.

Name	Designation	Present	Absent
Mr. Kishore Kotecha	President	7	2
Mr. Ajay Palande	Vice President	9	0
Mr. Paresh Parmar	Hon. Secretary	9	0
Mr. Raju Dhobi	Jt Secretary	7	2
Mr. Mahesh Mundra	Jt Secretary	7	2
Mr. Pratik Mehta	Treasurer	6	3
Mr. Balshiram Gadhave	EC Member	5	4
Mrs. Indira Nair	EC Member	7	2

Name	Designation	Present	Absent
Mr. Kalpesh Patil	EC Member	8	1
Mr. Krunal Kotecha	EC Member	7	2
Mr. Rupal Panchal	EC Member	6	3
Mr. Vinay Nair	EC Member	5	4
Mr. Yatish Patali	EC Member	5	4
Mr. Mustafa Shaikh	Youth Group	7	2
Mrs. Sangita Parmar	Women Group	8	1

AGM of HSMC Last Year:

HSMC conducted 27th Annual General Meeting on 25th Aug'2019 at M.L.T Auditorium, K.E.M Hospital. Total 65 PwH with their parents 110 persons in total attended this Annual General Meeting. Also HSMC conducted Adjourned Annual General Meeting on 29th September 2019 at C.V.T.C Auditorium, K.E.M Hospital. PwH with their parents total 65 persons were attended the Annual General Meeting.

In this meeting we conducted Election for which Ms. Aditi Saxena (Lawyer Mumbai High court) was appointed as an election officer. 13 members were selected for "New Executive Committee" for the period 2019 – 2021. Activity report and financial report was presented. The meeting was ended with Vote of Thanks followed by lunch.



HFI AGM 2019:

Mr. Rupal Panchal (President), Mr. Paresh Parmar (Vice President), Mr. Ajay Palande (Hon. Secretary), Mrs. Sangeeta Parmar (Women Group Representative), Mr. Raju Dhobi (Youth Group Representative), Mrs. Indira Nair (Women Coordinator of West Region), Mr. Kalpesh Patil (E.C Member of HSMC) had attended HFI AGM at Delhi on 21st and 22nd Sep'2019.



ACTIVITY REPORT

Education Help

With the help of donors HSMC has given Rs. 5,000 each as educational help to 14 Children with Hemophilia, on 25 Aug 2019. Another educational help was given to 7 CwH from our donor Mrs. Mala Jagtiyani through Mrs. Indira Nair. Each CwH received education help of Rs. 30,410/- on 13th Sep 2019 at HSMC Office.



Women Group Meeting:

Women group of HSMC arranged a meeting at HSMC office on 12th Oct'2019. Total 15 women members attended this meeting with staff. We had women group committee election at this meeting. Mrs. Sangita Parmar was nominated as women chairperson of HSMC by everyone. We raised some donation from women participants who attended the meetings and explained them the importance of fundraising and how they can raise funds. Two new women with bleeding disorder have attended the meeting and discussed their problems. Then the meeting ended followed by snacks.



Get Together with Save One Life Team:

Mr. Chris Bombardier (Executive Director), Save One Life team and Mrs. Usha Parthasarathy (SOL India Coordinator) visited Mumbai Chapter and had interviews with Scholarship beneficiaries. Mr. Nilesh Suryavnsi, Vyankatesh Paralikar, Yogi Parmar, Shubham Dhoot and Ganesh Shelar from Nashik were interviewed and they were really happy to see the progress and improvement in their lives. They will show these videos over there to get more support to others. We are really grateful to them for bringing a change in the lives of Hemophiliacs and selecting Mumbai Chapter. Also Hemophilia Society Mumbai Chapter had organized get together with Save One Life team. Our CwH with their parents and Executive members had also participated in this program. Welcomed to guest by Indian tradition.

The program had started with the Introduction session of Save One Life Team and then we discussed about day to day life with CwH. As a token of Love and Respect, we had also given shawl & coconut according to Indian tradition to Save One Life team and Mrs. Usha Parthasarathy. We click some memories and happiness followed by providing Snacks and Diwali Faral to the presenters.



ACTIVITY REPORT

Founder Day Celebration:

Hemophilia Society Mumbai Chapter celebrated Founder Day in tribute of our great Leader & Founder Late Shri Ashok B Verma and also arranged Educational Meet of Inhibitor Patients of Hemophilia Society Mumbai Chapter and Hemophilia Society Thane Chapter on 24th November'2019 at C.V.T.C Hall, K.E.M Hospital. Total 58 people which included 33 PwH with their parents attended this Founder Day & Inhibitor Patients Meeting. Mr. Kishore Kotecha (President) welcomed all attendees. Meeting started with National Anthem followed by tribute of Late Shri Ashok B Verma and lighting of lamp by our guest Dr. Devila Sahu along with Executive Committee Members, Youth Group, Women Group and CwH.



On this occasion Dr. Devila Sahu remembered the founder late Shri Ashok B Verma and her journey. We also conducted awareness on inhibitors development and factor non availability in hospital followed by an interactive question and answers session.

Many thanks to Dr. Devila Sahu for her valuable time and advices and also to the patients, parents and everyone who attended this programme and made it a success. The meeting was ended Vote of Thanks followed by lunch.

Haldi Kumkum Celebration by Women of HSMC



Women group of HSMC organised Haldi Kumkum program at HSMC office on 8th Feb'2020. Total 40 women members and their children attended this meeting with staff.

We invited Dr. Aarti an assistant of Dr Kirti, she guided us on meditation and physiotherapy. Also KEM Hospital Dr. Suraj and Nurse Mrs. Akshata joined the program and enjoyed with us. In this program we felicitated **Shiv Sena Aamdar Mr. Ajay Chaudhary and his P.A. Mr. Sadashiv** for their support. The program ended followed by snacks.

Awareness Program at Arya Vidya Mandir School

Arya Vidya Mandir school at Bandra Kurla Complex had organised "Arya Prabha Diwas" on 12th February'2020 for this they invited our CwH between 8 to 12 years of age. Our 34 children participated and their parents, a total of 66 people participated in the event along with Ms. Indira Nair and Ms. Sheetal.

Our children enjoyed the dance and various games arranged by the students from AVM. Also hemophilic children performed dances in the event. 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 of medicines worth Rs. 20,000.



ACTIVITY REPORT

Women Group Picnic

Women group of HSMC organized picnic with women group of Thane chapter at the Balang farm house (Vasai) on 8th March'2020. Total 50 to 60 women members and their children with KEM Hospital doctors and nurse. They all celebrated "International Women's Day" and also on this occasion they discussed about their problems. Special thanks to Hare Krishna for giving sponsorship.



Support to PwH in Covid 19

Due to Covid 19 pandemic situation HSMC gave a total help worth Rs.16,000/- to 9 PwH. Some Executive members of HSMC personally gave help to PwH families. Women group members Mrs. Jumana Colombowala, and Mrs. Sangita Parmar gave help to some PwH and CwH families during this pandemic situation. Also, Mrs. Jumana have done fund-raising through social media for patient help. Mr. Jigar Kotecha and Mr. Krunal Kotecha helped some PwH with their own Factor. We highly appreciate their support.

HSMC had placed Factor at six different places in the city during the lock down time for PwH. During this time we have distributed approximately 50,000 IU of Factors to PwH, most of it was given free of cost. Mr. Ajay Palande and HSMC staff was in touch with doctors to make treatment available in this difficult time. Mr. Paresh Parmar has been co-ordinating with HSMC staff and PwH, issuing them Travel Request Letter so that they should not face any difficulty in getting treatment.

Project Home Treatment:

Under this project, therapist goes to the patient's house and gives regular therapy rather than patient coming to hospital. This saves not only the patient's daily traveling but also helps them in preventing bleeding. This project will save further damage to joints of the patients.

The Project ran for about 9 years from October'2011. This year under this project on an average 11 therapist doctors have supported for 139 home visits during this period. The total fund spend on this project was about Rs. 68,100.



ACTIVITY REPORT

Save One Life (SOL) Report

'Save One Life' an organization 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 their Sponsorship Programme, Scholarship Fund, Micro-Enterprise Fund and Project Share since many years.

This year, under SOL Sponsorship project total of 33 beneficiaries received donation. Fund received in total USD \$ 9900.94 (Rs. 7,22,757/- Approx). This help means a lot to Hemophiliacs which was used for various needs like education, food, medicine, celebration and public transportation.



Apart from regular sponsorship, we have received support of Rs. 59,911/- (\$ 820.77) for Aakash Rane for studying MCA second year in BVIMIT and under Micro Enterprise we have received support of Rs. 73,520/- (\$ 1007.09) for Chetan Motiwaras to purchase iMAC system for his freelancing job of video editing.

Support and Donation for Person with Hemophilia:

- ✦ In this year from Oct'2019 to Aug'2020, we have received donation of Rs. 52,800/- from Mr. Roomy Daruwala, Rs. 30,000/- from Ms. Aban Irani, Rs. 20,000/- from Mrs. Sanjivani Diwan, Rs. 10,000/- from Mr. Shivraj More, Rs. 10,000/- from Anupama Mundra, Rs. 5000/- from Mr. Arunkumar Thakkar. Rs. 3003/- from Mr. Ajay Kumar, Rs. 3000/- from Mr. Ali Hasnain Kanjariwala, and Rs. 10,870/- from Mr. Shyam Khatri. We are providing medicine for free and subsidized cost from this fund to our PwH.
- ✦ Received medicines worth Rs. 20,000/- from Arya Vidhya Mandir School.
- ✦ We are providing free food (Lunch & Dinner) to PwH admitted at KEM Hospital. Our this activity is majorly supported by M/s. Pranav Associates (Mrs. Vaishali Nakashe, Mother of PwH). We have received total donation of Rs. 75,000/- in this year.
- ✦ HSMC is giving monthly Rs. 1,000/- for purchasing Grocery Items to 5 PwH below poverty line families. For this we have spent Approximately Rs. 55,000/- this year.
- ✦ Homeopathy Camp is arranged every month 3rd Sunday, attended by 20 to 22 PwH. In this camp PwH only pays the doctor consultation fees and we are giving medicine to them free of cost.

USEFUL INFORMATION

KEM HOSPITAL OPD 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 Orthopaedic Bldg., Opp. Tata Hospital, Parel, Mumbai.

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

With Prior Appointment From Dept. Phone No. 022-24107044

(Govt. Holiday Center will remain close)

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)

(Govt. Holiday Center will remain close)

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

(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)

Dental Department OPD:

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)

USEFUL INFORMATION

KEM HOSPITAL OPD TIMINGS

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

GI Medicine - Gastroenterology (HCV) Dept. OPD Timings:

Doctor's Name: Dr. Aaksh Shukla

Address: Sion Hospital, OPD No. 27, 1st floor, Opd bldg. Sion, Mumbai.

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

Old Patient:- Available on Thursday & Saturday - Case Paper Time 08.80 am To 10.30 am

(Govt. Holiday Center will remain close)

Privet Dental Clinic:

Doctor's Name: Dr. Mehul Mehta

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

Phone: 9820401367

Timing: 10.00 am To 07.30 pm

Privet 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.

E-mail: dr.hiralbothra@gmail.com

Mob No: 7738917504

Visits at Hemophilia Society For Camp Every Month 3rd Sunday Only.

Time: 10.00 am To 03.00 pm

Hemophilia Federation (India)

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

Phone: 011-45034951 / 45034972 / 41552819

E-mail: ceo@hemophilia.in

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

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Organization (MESCO)
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Novo Nordisk India Pvt.Ltd.
Pamarox Pvt. Ltd.
Rabia Abdul Kader Millwala Trust
Rangoonwala Foundation
Reliance Life Science
Shire Pharmaceuticals
Shri Sidhivinayak Mandir Trust
St. Micheal Church
State Blood Transfusion Council
Unitedway of Mumbai
Valentine Charitable Trust
World Federation of Hemophilia

Individuals:

Angha Tillu
Akshata Rahate
Devang Shah
Jumana Colombowala
Kishore Kotecha
Laurie Kelley (USA)
Neena Shah
Roomy Daruwala
Shyam Khatri
Usha Parthasarathy
Vaishali Nakashe

Doctors:

Dr. Chandrakala S	Dr. Saurabh Phadke
Dr. Amit	Dr. Karuna Nadkarni
Dr. Ketan	Dr. Kirti Patil
Dr. Leo	Dr. Mamta Manglani
Dr. Akash Shukla	Dr. Manisha Madkai
Dr. Savita Rangarajan	Dr. Mehul Mehta
Dr. Pranoti Kamat	Dr. MM Desai
Dr. Aruna	Dr. Nanda Pai
Dr. Bipin Kulkarni	Dr. Pravin Bangar
Dr. Deepak Gupta	Dr. Shrimati Shetty
Dr. Devila Sahu	Dr. SS Mohanty
Dr. Farah Jijina	Dr. Jayashree Kale
Dr. K. Ghosh	

Our Marathon Page Donor:

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Hemophilia Society Mumbai (Chapter)

Affiliated to Hemophilia Federation (India)

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Admin Office : 205, Sai Apt, 64-B, Swarajya Bhavan CHS., Bhagwan Rao Parelkar Marg, Parel Village, Mumbai - 400012. **Phone** : +91-96533 24634 +91-22-24158315. **E-mail** : mumbai@hemophilia.in