

Hemophilia Without Disability,
Children Free of Pain

25 Years

Of Care, Commitment & Togetherness



HEMOPHILIA SOCIETY MUMBAI (CHAPTER)
25th Annual Report 2016 - 2017

Message From the Desk of President



Dear Members and PwH Brothers With Family Friends

It gives me immense pleasure to note overall development on the Silver Jubilee year of the organization. Finally we got our own day care center for immediate on demand treatment as well as prophylaxis treatment for some children. Our center i.e. KEM Hospital is recognized internationally as "HEMOPHILIA COMPREHENSIVE CARE CENTER (HCCC)" & therefore, responsibility of our chapter is also increased. Without fixing a goal, no organization can reach to success. I am proud to say that we have almost achieved the important targets & near to achieve our goal i.e. Hemophilia without Disability, Children Free of Pain.

Humanitarian Aid Program of WFH is about to end in 2018. National Health Mission is now sensitized while making policies & funding for procurement of AHF. However, you are aware that due to some unexpected situations, we have faced shortages of AHF, for continuous supply of AFH we must find some alternate way so that all the PWH get enough quantity required and live without pain and disability. Hemophilia is now included in Disability Act 2016 and we need to understand the provisions of Act, its benefits to PWH & focus to implement the Act.

I am proud to say that our organization is unique & working in systematic and unique manner with single voice. We need to follow the guidelines framed by WFH & HFI so that we get quality product and advanced treatments for improvement of quality life. We still need to focus to reach in the main stream of society and achieve good education, good health, good job or business.

We are special and this is a good opportunity to strengthen ourselves. I am proud to say that our chapter has completed 100% NHR and in the final stage of linking with Aadhar Card. The proper documentation and accountability is our strength equal opportunity is our motto; here everybody needs to be as a watch dog.

Finally I emphasize to strengthen our Women Group and Youth Group so as to create self help group and also second line of the organization. Using Social Media now we are on finger tips to reach each other. Only we need to speak and address all our problems and try to find out the solutions. Regular exercise is the key of success of our health. Through various projects we are trying to balance all and wish you all to success in the life.

I remain thankful to all of you, All Executive Members, Women Group and Youth Group for supporting to strengthen the organization for giving me an opportunity to work on all the various posts including EC Member, Secretary, Vice President and President for 14 years & now as a Regional Council Chairperson, West Region, HFI.



Balshiram V. Gadhave

President



Hello Doctors, Donors and Members,

It gives me pleasure to welcome you all for attending our 25th AGM. During the year the Mg. committee, Youth Group and Women group have arranged many camps and events for awareness and learning about living with hemophilia and hope that you all benefitted by participating in the same. The society has given support for home therapy, scholarship and eco-rehabilitation as per fund available. The Society has celebrated its silver jubilee and world hemophilia day with huge participation of yours.

During the year the committee has to put more effort for factor availability in the Govt. Hospitals as the Govt. policy for factor purchase changed. Because Govt. factor availability is irregular it is my advice to all hemophilic to

do regular physical exercise and depend less on factor infusion. Some of our members finds homeopathy as suitable alternative medicine to reduce bleeding episode. Hope you could try the same.

The committee has a goal to provide occupational / physical therapy at PWH home, but finds it difficult in absence of availability of therapist doctors and funds. I personally request you all to help society committee in raising funds to achieve goal of providing free home therapy and free medicine. I request you to form area wise patients group and have regular meeting to share your treatment problems and find solution to other social and economic problems. You are requested to visit treating doctors at regular intervals to keep your joints healthy. Lastly I request you to keep your outstanding dues low for the benefits of all members of the society.

I personally thank all our donors, doctors, supporters and Mg. committee, youth and women group and staff members for their support for the Society activities and working. Wish you all happy and pain free life in the coming year. **Jai Hind !**

Colombowala. Z.

Colombowala Zulkef

Vice- President

Message By Dr. Chandrakala



We in the department of hematology are treating PWH for more than 25 years. Till last 6 to 7 years, cryoprecipitate and FFP was the main line of therapy for PWH in India. With the help of DHS and BMC, all our patients are receiving CFCs. All of them were on episodic therapy. Since last 2 years, few of our children are started on prophylaxis therapy. This has reduced direct and indirect costs of patients as well as their families. Now more and more patients are aware of prophylaxis treatment and benefits of it. In the city of Mumbai to travel to hospital for prophylaxis is a major task and they had to spend lot of time to come to hospital for prophylactic therapy. Our aim was to make them independent as well as train parents for infusion in their children for home therapy.

We conducted 8 sessions of training over a period of 3 months, starting 1 month after start of prophylaxis. After 3 months of training, all of the parents were trained in infusion of their children and after 8 monitored sessions were shifted to home care. Currently, there are 65 patients between 1 -10 years of age on prophylaxis and out of these 18 patients on home therapy.

With availability of long acting factor from WFH, we extended the prophylaxis programme even further till 15 years of age. Patients were 100% compliance and improved quality of life, reduced joint bleeds and life threatening bleeds, reduced school / college absenteeism. 4 patients are currently on ITI therapy.

In KEM hospital, we have 911 PWH registered till date and 280 patients registered in last 1 year. With availability of prophylaxis and dramatic improvement in QoL of both patients of both parents and patients, now parents themselves come asking for prophylaxis to our center.

Hopefully, all hemophilia patients will have access to CFCs in nearby hospitals and prophylaxis therapy will be given to every PWH in our country. Along with management of hemophilia, carrier testing and prenatal testing is equally important.

Dr.Chandrakala. S.

MD., DM Fellowship in leukemia/BMT

Professor (Adhoc), Dept of Clinical Hematology, KEM Hospital, Mumbai, India.

Message From Dr. Jayashree Kale



My message to the youth group

Celebration of the annual day of the youth group, is a moment of pride and pleasure. The hemophiliacs I have seen from the age of 0-15 are now competent as independent professionals. In the past 25 years have plodded with the PWH and have witnessed the most difficult times in their care. Hemophilia was once a matter of great concern in the 1990's when the treatment with basic products was not available, with better access to the AHF hemophilia it became better. With advanced products like long acting factor, prophylaxis and free availability of factor the status of hemophiliacs seems to have bettered.

There are a lot of challenges that have yet to be dealt with, especially for the one who have developed inhibitors, synovitis, deformities in the target joints. Prevention of recurrent bleeds through prophylaxis, education on appropriate exercise programs and nutritional care form the crux of hemophilia care today. Corrective surgeries are a need of the day for the PWH with deformities. Regular exercise programs will indeed add to the outcomes of prophylaxis and on demand therapies. Being an inherited disorder, problems in different forms are always anticipated. It is thus important to have more well equipped comprehensive care centers with dedicated professionals having the expertise in hemophilia. Persistent availability of AHF is a prime need.

We, together should join hands and attribute our efforts to make available state of art comprehensive care centers, abundant factor to most of the parts in India. Hope to see the future of hemophiliacs as having no disability and no pain.

Wishing all the PWH of Mumbai Chapter a great going!

Dr. Jayashri Kale

Professor and HOD
Occupational Therapy
GSMC, KEMH, Mumbai, India

Executive Committee

Report of Executive Committee Meetings:

15 executive committee meetings held during the period for planning and executing the society's activities from August 2016 to July 2017

Name	Designation	Present	Absent
Mr. Balshiram Gadhave	President	11	4
Mr. Z. Colombowala	Vice President	11	4
Mr. Ajay Palande	Secretary	15	0
Mr. Rupal Panchal	Treasurer	5	10
Mr. Chetan Motivaras	Jt. Secretary	13	2
Mr. Yatish Patali	Jt. Secretary	5	10
Dr. Anuradha Samant	EC Member	2	13
Mrs. Asha Gupta	EC Member	7	8

Name	Designation	Present	Absent
Smt. Indira Nair	EC Member	15	0
Mr. Kishore Kotecha	EC Member	6	9
Mr. Krunal Kotecha	EC Member	7	8
Mr. Mahesh Kadam	EC Member	4	11
Mr. Nilesh Solanki	EC Member	3	12
Mr. Paresh Parmar	EC Member	11	4
Mr. Vinay Nair	EC Member	0	15
Mr. Subhash Desai	EC Member	3	10

Membership as on 31 March 2017:

Total **30 new PwH members** registered during the year from 1st April 2016 to 31st March 2017. We were managing membership record manually which is now managed by National Hemophilia Registry (NHR) Software online. We have identified 13 duplicate entries which are corrected, we have also removed 97 PwH who were expired since establishment out of which 7 PwH members expired during the year.

As on 31 March 2017, our final membership details are as follow:

Registered Members With in Mumbai: 790

Registered Members Out of Mumbai: 256

Total Membership: 1046

Did you know?

“According to India’s population, there must be over 70,000 Hemophiliacs out of which only 16,000 have been identified.”

“A Person with Hemophilia is capable of full normal life if he is helped in his childhood and youth with proper medical support.”

Anti Hemophiliac Factor Consumption:

Year	Factor VIII		Factor IX		FEIBA		Novo 7	
	2016-17	2015-16	2016-17	2015-16	2016-17	2015-16	2016-17	2015-16
Paid	4,46,618 i.u.	3,60,617 i.u.	2,45,400 i.u.	1,35,500 i.u.	28,000 i.u.	28,500 i.u.	—	—
Donated	1,680 i.u.	51,942 i.u.	74,240 i.u.	44,240 i.u.	502 i.u.	4,000 i.u.	213.2 mg	79.4 mg
Total	4,48,298 i.u.	4,12,559 i.u.	3,19,640 i.u.	1,79,840 i.u.	28,502 i.u.	32,500 i.u.	213.2 mg	79.4 mg

Summary of Financials:

Summary of Balance Sheet	Year 2016-17	Year 2015-16	Summary of Profit & Loss	Year 2016-17	Year 2015-16
	Rs. In Lacs	Rs. In Lacs		Rs. In Lacs	Rs. In Lacs
Trust Funds and Other Funds	130.60	127.91	Gross Income & Closing Stock	98.74	89.05
Fixed Assets	12.71	13.74	Total Expenditure & Opening Stock	96.47	86.12
Investments	83.26	93.99	Surplus	2.27	2.92

Diagnosis & Test done at IIH, KEM Hospital:

Factor Assay done for 344 persons with bleeding disorder, out of which the data of Hemophiliacs is as under:

	Factor VIII	Factor IX	vWD	Rare Factor
Severe	78	13	—	17
Moderate	34	5	29	3
Mild	37	18	—	13
Inhibitor Positive	97	—	—	—
Other	---	—	—	—
Total	246	36	29	33

Did you know?

“A father with Hemophilia can never give his disorder to his son.”

“Hemophilia, in one third of the cases, arises from spontaneous mutations. It means, any of the so called healthy couples could get a Hemophiliac son at any point of time.”

“There are many Hemophiliacs who have become Doctors, Engineers, MBA and Business Owners. Hence, the donation given is for a noble cause towards fulfilling the dream of Hemophiliacs.”

Total 76 Carrier Detections done in Hemophilia A and B families by DNA analysis:

In the current year 76 females (66 Hemophilia A and 10 Hemophilia B females) were referred for the detection of carrier status. The analysis was performed by RFLP analysis using the polymorphic markers. 39 females were found to be carriers whereas 37 females were non carriers.

Total 67 Prenatal Diagnosis done by chorionic villus sampling procedure:

54 females belonging to Hemophilia A, 6 females belonging to Hemophilia B and 3 vWD families were referred in first trimester for prenatal diagnosis. 12 fetuses were found to be affected. HIV/HCV tests also done in ICMR.

Women Group Meetings:

Apart from the festival activities, awareness activities and Society related activities, there were 3 meetings during the year wherein we discussed in detail about the personal, school related issues, child behavior issues and solutions thereon.



We arranged a special meeting for VWD and female sufferers wherein they discussed about their problems and how they are getting treated for prolonged bleeds, hemoglobin levels etc. Few members from the Women Group participated in Standard Chartered Marathon. We celebrated Haldi Kumkum, Diwali, Christmas etc which was real enjoyment with games, music and lots of fun.

The beneficiaries of economic rehabilitation expressed their gratitude and are doing well. Knowledge sharing on Hemophilia was done by Mrs. Indira Nair through presentation on What is Hemophilia, Treatment, Chapters Functioning, HFI activities, various projects information of HFI and Save One Life, WFH information etc. This was an interactive session with lots of queries from the members which was appreciated by all.

Homeopathy Camp at HSMC:

Homeopathy Camp is being arranged every month on the 3rd Sunday wherein 20 to 25 PWH take benefit of the same. For the Homeopathy treatment, PwH only has to pay only for doctor consultation fees and the Society pays for their medicine.

AGM of HSMC Last Year:

HSMC Conduced 24th Annual General Meeting on 24th September 2016 at Jeevraj Mehta Auditorium, KEM Hospital. Total 124 members with their families attended the meeting. Where HSMC executive committee has produced minutes of last meeting, activity report, financials etc.





Celebration of Youth Group & Women Group Anniversary

Youth group had celebrated their 5th anniversary at Pali Beach Resort along with Women's group celebrating their 3rd Anniversary. WHERE WE invited about 109 participants. Dr. Jayshree Kale spoke on Importance of Muscle & Joint Management as Supportive to Factors in Hemophilia Therapy while Dr. Rohan Kolla spoke on Recent Advances in Management of Hemophilia in India.

We had a wonderful Q&A round with Mr. Prashant Kumbhalkar (Novo Nordisk) as he spoke on advantages of Novo 8 and youth EC shared their experience from last 5 years.



Diwali Festival Celebration

Women along with their Hemophiliac Kids and HSMC key persons along with youth members celebrated Diwali festival on 27th October 2016 at Hemophilia Society office. Everyone wished Happy Diwali to each other. HSMC distributed gifts and crackers. All enjoyed games, snacks and fireworks.



Children's Day Celebration

HSMC with the help of Novo Nordisk celebrated Children's Day on 14th November 2016. Program started with interaction with all kids followed by fun games of numbering.



Mr. Prashant Pawar and Mrs. Neeta Salunke, Novo Nordisk executives gave information with small PPT "PRISE" for taking care of Joints and Muscle Bleeding in Hemophilia. Managing Hemophilia beyond clotting factor and Role of Physiotherapy and Exercise. Also they distributed ARM SLING to all CWH.

Educational Camp with HCV Positive Hemophiliacs

We have arranged a meeting with HCV PwH on 4th December 2016. In that meeting Dr. Akash Shukla gave an informative speech on HCV treatment, Liver Health, Healthy Living etc. Total 125 persons including PwH and family members attended this session.



Activities During the Year

Christmas Get Together

Youth group along with HSMC organized Christmas party for children between age group of 5 - 15 years on 25th December 2016 wherein 60 CwH and their parents, Youth Group, HSMC Committee Members total 120 people



were present. The program started with interactive session. We felicitated all Guest and program supporters. The much awaited surprise program of puppet show and magic show, where all kids were participating and enjoying to their fullest. A sweet little Angel singing jingle bell song, Mr. Ajay Palande our Secretary in full mood dressed up as "Santa Claus" distributed gifts. All kids enjoyed delicious Cake and Chocolates followed by Lunch.

Ms. Andrea Echavez and Mr. Mukesh Garodia Visit HSMC

Ms. Andrea, the president of Hemophilia Advocates Philippines and Mr. Mukesh Garodia, Vice President Development HFI visited Mumbai Chapter on 5th Feb 2017 where Ms. Andrea shared her experience as a sufferer and care taker. She informed about the working of Hemophilia Advocates Philippines. Mr. Mukesh too shared his experience and working of HFI. A detailed presentation on women group activities were shared by Ms. Indira Nair while Ms. Andrea shared complete details about the formation of Hemophilia Advocates Philippines and their work, fund raising, diagnostic facilities, awareness programmes etc.



We had Haldi Kum Kum celebrations with 22 Women members, a few of them who are VWD, hemophiliacs. Haldi Kum Kum gifts were distributed after the traditional celebration and then off to Gateway of India.

International Women Day celebration

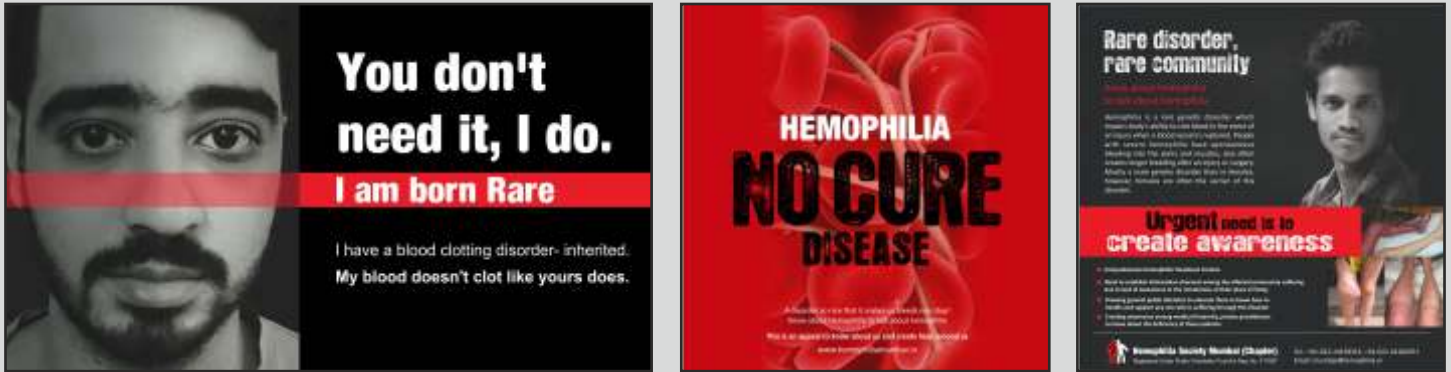
Celebrated Women Day at HSMC office on 11th March'2017. Members shared their problems, concerns and stigma related issues. 15 members including the newly registered members attended this meet. Presentation made by Mrs. Indira Nair on What is Hemophilia, Treatment and care, information on Hemophilia, HFI, WHF, Carrier and prenatal detection etc etc. Members expressed their desire to attend such meeting often.

Annual General Women Meet of WGHFI at Delhi on 3rd and 4th June 2017

Ms. Indira Nair (Women Group Chairperson) with Ms. Gita Jain and Ms. Megha Dhuri attended this AGM. Total 74 women from 24 chapters were participated in this workshop. In this meeting Ms. Indira Nair was selected as a Western Region – Coordinator.

Positioning of Hemophilia in General Public

To bring awareness and support towards Hemophilia, HSMC has given an assignment to an agencies Smoke Communication and Pratima Advertising. They have positioned Hemophilia as "**BORN RARE**" because it is a rare genetic disorder. A community who are suffering yet surviving and performing, though the victims of this fatal disorder, are seeking financial/ social support from general public and government.



Hemophilia Society with support of Smoke Communication has hosted a musical event **By The Rare - For The Rare** with extra-ordinary Artists like Maestro Uttam Singh, PadmaShri Anup Jalota, Rupa Chak and Visually Impaired Diwakar Sharma of lil champs. The event was attended by an illustrious audience. The agency have published an advertisement in news papers, put hoardings at various places of Mumbai, Radio City a radio channel has broadcasted promotional messages for five days.

Standard Chartered Marathon 2017:

Hemophilia Society Mumbai (Chapter) took part in the standard Chartered Marathon – disability run – 2km on 15th Jan'2017. In all 16 of us participated including committee members, PWH & their parents and our well wishers to spread awareness on Hemophilia. This year we invited Dr. Alwin Christuraj from Chennai who participated in Full Marathon (42km) and he successfully finished in 7.15 hrs without any bleed.



School Awareness Program at Arya Vidya Mandir – Bandra

Arya Vidya Mandir Bandra Kurla Complex was organised on Arya Prabha Diwas on 13th February 2017 on this day they invited our CWH between 8 to 16 age group. In all 35 children participated and their parents total 55 no their presents. Our children enjoyed the various games arranged by the students from AVM. Each child were gifted with ludo games, Bags, Colour box as gift. In the meantime Ms. Indira Nair & Ms. Jumana Colombowala took nice session with the parents wherein they shared their experiences.





College of Social Work, Nirmala Niketan Centre – 22nd February'2017
 Mrs. Indra Nair, President- Women Group and Mr. Ajay Palande, Secretary presented on "What is Hemophilia and it's treatment", the activities of HSMC including Youth and Women Empowerment. She gave some of the examples of the members who have been successful in their lives in spite of their fight with Hemophilia and the members we lost due to serious bleeds.

Hemophilia in News

लोकमत
हिमोफिलियाग्रस्तांची समस्या : शासनाच्या निविदाप्रक्रियेचा फटका
औषध टंचाई रुग्णांच्या मुळावर

मिर्झा : हिमोफिलिया हा मरणाची धमकी असणारा आजार आहे. यातून होणारे रक्तस्राव हे खूपच वेगळे असून त्याचे उपचारही वेगळे असून त्यासाठी खूपच महागडे औषधे लागतात. या औषधांची टंचाई रुग्णांच्या जीवनात मोठ्या प्रमाणात त्रास पोहोचवते. शासनाच्या निविदा प्रक्रियेचा फटका रुग्णांच्या जीवनात मोठ्या प्रमाणात पोहोचवतो आहे. शासनाच्या निविदा प्रक्रियेचा फटका रुग्णांच्या जीवनात मोठ्या प्रमाणात पोहोचवतो आहे. शासनाच्या निविदा प्रक्रियेचा फटका रुग्णांच्या जीवनात मोठ्या प्रमाणात पोहोचवतो आहे.

हिमोफिलियाच्या औषधांचा तुटवडा काय

मुंबई : मरीजींनी औषधांच्या टंचाईमुळे जीव नश्ट होण्याची भीती असल्याने रुग्णांच्या कुटुंबातून खूपच तणाव जाणवतो आहे. शासनाच्या निविदा प्रक्रियेचा फटका रुग्णांच्या जीवनात मोठ्या प्रमाणात पोहोचवतो आहे. शासनाच्या निविदा प्रक्रियेचा फटका रुग्णांच्या जीवनात मोठ्या प्रमाणात पोहोचवतो आहे.

HC: Streamline med supply for haemophiliacs

Mumbai: The Bombay high court on Monday directed the state government to evolve a proper mechanism to ensure that there is no shortage of medicines for haemophiliacs. "Make a fool proof mechanism so that at any given point of time there is not a single patient who does not get the medicines," said a bench which heard a public interest litigation where the petitioners are haemophiliacs. They complained about non-availability of medicines in six day care centres in Mumbai.

जीवरक्षक औषधांअभावी हिमोफिलिया रुग्ण हवालदिल

मिर्झा संस्थानतून हिमोफिलिया सोसायटी चेंबरचे नाकडे

मिर्झा : हिमोफिलिया हा मरणाची धमकी असणारा आजार आहे. यातून होणारे रक्तस्राव हे खूपच वेगळे असून त्याचे उपचारही वेगळे असून त्यासाठी खूपच महागडे औषधे लागतात. या औषधांची टंचाई रुग्णांच्या जीवनात मोठ्या प्रमाणात त्रास पोहोचवते. शासनाच्या निविदा प्रक्रियेचा फटका रुग्णांच्या जीवनात मोठ्या प्रमाणात पोहोचवतो आहे.

Patients suffer as haemophilia drugs short in supply

MUMBAI: Sagar Dhonde visited every hospital in Mumbai, pleaded with the public health department and eventually travelled all the way to Nashik for the medicine that would save his six-year-old haemophiliac son from bleeding to death.

The search for the lifesaving drug has become a routine thing for more than 4,300 haemophiliac patients across the state for the past seven months. The gap in the government's e-tendering system has failed to ensure easy availability of anti-haemophilia drugs.

"For five days, we kept managing with our meagre stock and..."

हीमोफीलिया के मरीजों को नहीं मिल रही दवा

मुंबईचे रुग्णांच्या औषधांच्या टंचाईमुळे जीव नश्ट होण्याची भीती असल्याने रुग्णांच्या कुटुंबातून खूपच तणाव जाणवतो आहे. शासनाच्या निविदा प्रक्रियेचा फटका रुग्णांच्या जीवनात मोठ्या प्रमाणात पोहोचवतो आहे.

राज्यभरातील डे केअर सेंटर उपचाराविनाच औषधांअभावी रुग्ण व्हेंटिलेटरवर : आज जागतिक हिमोफिलिया दिन

औषधांअभावी रुग्ण व्हेंटिलेटरवर : आज जागतिक हिमोफिलिया दिन

राज्यात हिमोफिलिया रुग्णांसाठी शासनाचे २५ कोटी रुग्णांची वारंटवडी विभागाच्या अंतर्गत आहे. शासनाच्या निविदा प्रक्रियेचा फटका रुग्णांच्या जीवनात मोठ्या प्रमाणात पोहोचवतो आहे.

हिमोफिलिया रुग्ण व्हेंटिलेटरवर

मिर्झा संस्थानतून हिमोफिलिया सोसायटी चेंबरचे नाकडे

मिर्झा : हिमोफिलिया हा मरणाची धमकी असणारा आजार आहे. यातून होणारे रक्तस्राव हे खूपच वेगळे असून त्याचे उपचारही वेगळे असून त्यासाठी खूपच महागडे औषधे लागतात. या औषधांची टंचाई रुग्णांच्या जीवनात मोठ्या प्रमाणात त्रास पोहोचवते. शासनाच्या निविदा प्रक्रियेचा फटका रुग्णांच्या जीवनात मोठ्या प्रमाणात पोहोचवतो आहे.



25 Year Celebration - World Hemophilia Day



This year Hemophilia Society Mumbai Chapter completed 25 years it's a Silver Jubilee in serving Hemophilia Community, on 7th May 2017 at Sion Hospital auditorium, with audience 545 PwH, Family and well wishers celebration begins.

Event started with welcoming the guests at the red carpet, with each guest being interviewed by the red carpet team. The interviews were

simultaneously broadcasted on Facebook Live, on the Youth Wing page. All the guests congratulated the Society on completing its silver jubilee, and were proud to be associated with it.



There was a fabulous national anthem, constituting of the Youth Members & HSMC staff. After the lighting of the lamp, we had the wonderful ladies from Women Group of the society singing the motivational song i.e. "Itani Shakti Hame Dena Data", which was very well received by the audience and after that program started with Ganesh Vandana.

A brief history was presented by Mr. Girishbhai, as he turned back the time and took the audience back into the Society's nascent days. He displayed the very tables and rooms where the Hemophilia Society was formed, and reached where it is today.



HSMC Felicitated to all the guest coming from all over the city, Doctors, Donors, Old HSMC Staff and PwH who had passed SSC, HSC, Graduation.

Our PwH Achintya Gupta played nice songs on piano, Rutika Phugaonkar (VwD) and Sangita Sarak (Sister of PwH) each gave beautiful dance performance. All the members and children enjoyed the Orchestra and a sumptuous meal organized by the Society.



Projects Update

Save One Life (SOL)

Save One Life is a project run by an international organization LA Kelley Communications Inc. that offers, individuals, families, companies and / or organizations the opportunity to sponsor a child or adult with a bleeding disorder in a developing country. Ms Diane who is currently associated with BioMatrix in Research & Education Development is also one of the biggest sponsors under Save one life sponsoring children's from Mumbai and Thane visited along with her husband and daughter on 8th April to 12th April 2017. During her husband visit, her daughter Erin, along with Mrs. Indira Nair and Mr. Krunal Kotecha who coordinates with SOL on behalf of HSMC along with Mr. Sunil Jadhav, Mr. Suraj Singh visited the sponsored families home's where they received a warm welcome from the families full of emotions. They also visited patients at KEM hospital to have a look at the level of treatment given to the PwH and met specialist doctors treating Hemophilia. She met Dr. Jayashree Kale who heads Occupational Therapy department and Dr. Shreemati Shetty a scientist at ICMR, both significantly contributing for hemophilia.



On 9th April 17 we have arranged a meeting with SOL PwH and their parents, the meeting was coordinated by Mr. Yatish Patali, Mr. Vyankatesh Parlikar, Mrs. Indira Nair, Mr. Kishore Kotecha, Mr. Krunal Kotecha, Mr. Chetan Motiwaras and our Youth Group Member Mr. Prasad Shinde. They had one on one interaction with each other. After this meeting we arranged Open Deck bus picnic. All SOL PwH enjoyed Mumbai sightseeing along with some snacks.

Scholarship Program Project by Save One Life



Received Rs. 66,977/- to Mr. Darshan Hatnolkar (Factor – XIII) He is studying MBA Finance. And Rs. 52,992/- to Mr. Aniket Kadu (Factor - VIII) under Save One Life – Scholarship Program. He is studying BE Pharmacy. Mrs. Indira Nair completed all related documents and follow-up with SOL team.



Micro enterprise Project by Save One Life

Mrs. Indira Nair coordinated with Mrs. Usha Parthasarthy (SOL project coordinator from India) and Ms. Martha Hopwell (Executive Director Save One Life) and got help of Rs. 63,824/- to Mr. Ashutosh Pandit for starting his Travel business.

Educate a child with Hemophilia, HFI Project by Hans Foundation

Mumbai Chapter has in all 19 CWH registered under Hans Foundation where every CWH received Rs. 3600/- Half yearly to each CWH .

Carrier Detection & Pre Netal Diagnosis by HFI Project

Under this project total 2 beneficiaries received benefits :

- * PND Test – Sister of Mr. Chetan Motiwaras
- * CD Test – Sister of Saish Pawar (Kandiwali) & Sister of Monu Prajapati (Kandiwali)

Project under Foreign Donation (FCRA)

The Society has started the Nurses Project in October, 2011 with the fund support received from Velentine Trust of United Kingdom and donation received from Dr. Alison of U.K. from time to time. The initiative to start this project was taken by Dr. Alison, Ms. Indira Nair and Mr. ZulkefColombowala. The project was run under the guidance and supervision of Dr. DevilaSahu and KEM Occupational Therapist Dr. Jayshree Kale and Dr. KirtiPatil.

The Project ran for about 6 years from October, 2011 to July, 2017. Under this project on an average 20 therapist doctors have supported for 1874 home visits during this period. The total fund spend on this project was about Rs. 5.32 lacs. The society will revive this project on receipt of further funds.

HSMC Helping PwH

We give PWH medical help as follows

Rs. 25,000/- to Mr. Chetan Motiwaras for his Knee replacement treatment.
Rs. 50,000/- to Mr. Ashraf Siddique for his Imitation Jewelry business purpose.

In this year, we have received donations more then Rs. 5,000 as follows

Rs. 25,000/- donation from Mr. Roomy Daruwala
Rs. 25,000/- donation from Mr. Kaushal Didwania
Rs. 10,000/- donation from Ms. Varsha Joshi

We are providing free medicine / half rate from this fund to our PWH.

Received medicine worth Rs. 10,500/- from Arya Vidya Mandir

We distributed food coupons worth Rs. 79,200/- to PWH admitted at KEM Hospital. For this major help received Rs. 60,000/- from Ms. Pranav Associates (Mrs. Vaishali Nakashe, PWh mother). We have received Rs. 1,00,000/- from our donor Mr. Shyam Khatri for distribution of biscuits packets to PWH.

HSMC provides monthly Rs. 500/- for purchase of Grocery Items to 13 PWH below poverty line family. For this wh have spet total Rs. 66,500/-

HSMC has spent total Rs. 32,000/- towards HCV treatment for 3 PWH. (Mr. Satish Jagtap, Mr. Naresh Jain and Mr. Sanjay Pandey)

During this year we have received donation from Dr. Mala Jagtiyani Rs. 5,00,000/- out of which Rs. 3,00,000/- were issued towards education of PWH Mr. Rakesh, Ganesh & Yogesh and remaining Rs. 2,00,000/- for other PWH's. HSMC has also contributed Rs. 64,825/- and provided educational support 44 PWH in total.

Mrs. Jumana Colombowala collected donation worth Rs. 28,200/- for poor and needy PWH's education.

Did you know?

Anti Hemophilic drugs are essential drugs listed in the State / Central Pharmacy Essential Drug List and these are life saving medicines.

For your information; ESIC, CGHS, Railway, Public Sectors, some of the Nationalized Banks, Central Govt. / State Govt. / Corporation are purchasing Factors or reimbursing bills for their employees or their family members.

Some of our PWH have taken the benefit of Health Insurance Schemes during surgery / accident / treatment.

KEM Hospital:

Hematology OPD timings:

Doctor's Name: Dr. Chandrakala

Address: New Bldg., 1st Floor, KEM Hospital, Parel, Mumbai-400012.

Case Paper Time: 08.00 am To 10.30 am

OPD Timing: Monday & Thursday 10.00 am to 12.00 pm

Occupational Therapy Dept.:

Doctor's Name: Dr. Jayashree Kale

Timing: With prior appointment from Dept.

Phone No: 022-24107044

Address: C.V.T.C. Bldg., Room No. 4, Ground Floor, Opp. KEM Hospital, Parel, Mumbai-400012

Doctor's Name: Dr. Kirti Kene

Timing: 10.00 am to 3.00 pm

Phone No: 022-24136051 Ext.: 7562

Hemophilia Carrier Detection and Prenatal Diagnosis:

Doctor's Name: Dr. Shrimati Shetty

Address: National Institute of Immunohaematology, 13th Floor, New Multistoreyed Building, KEM Hospital Campus, Parel, Mumbai-400012

Phone No: 022-24138518 / 19, 24111161

Orthopedic Department:

Doctor's Name: Dr. Mohanty SS

Address: Ground Floor OPD No. 404 KEM Ortho Bldg. Opp. Tata Hospital, Parel, Mumbai-400012

Phone No: 022-24138518 / 19, 24111161

Homeopathy Clinic:

Doctor's Name:

Dr. Hiral Bothra - 7738917504

Dr. Omkar Kumat - 9595957741

Visits at Hemophilia Society: 3rd Sunday from 11.00 am to 3.00 pm with prior appointment from Society's office.

Doctor's Name: Dr. Digish Doshi

Address: 111 / Walkeshwar Road, Near Dani Sadan, Mumbai – 400006.

Phone No: 022-23610488

Ayurvedic Clinic:

Doctor's Name: Dr. Narendra Bhatt

Address: 15 / Bacchubhai Bldg., 1st Floor, Damodar Hall, J. Bhatankar Marg, Elphinstone Road, Parel, Mumbai - 400012.

Phone No: 022-24709844 / 24704611

Timing: 10.00 am to 1.00 pm & 4.00 pm to 7.00 pm

Timing Sunday: 10.00 am to 1.00 p.m (Thursday Close)

Dental Clinic:

Doctor's Name: Dr. Mehul Mehta

Address: Dr. Bhogilal Bhavan, 5th Mamalatadar Wadi, Malad (West), Mumbai – 400064.

Phone No: 9820401367

Timing: 01.00 pm to 7.30 pm

Doctor's Name: Dr. Chetan Bhanushali

Address: Jogeshwari (East), Mumbai.

Phone No: 022-28376097

HIV / HCV Clinic:

Doctor's Name: Dr. J. K. Maniar

Address: 597/101, J.S.S Road, Chira Bazar, Rajshila Bldg., Marine Lines, Mumbai – 400002.

Phone No: 022-22056538

Factor Available at Night & Holidays:

Name: Mr. Nilesh Suryavanshi

Address: Bldg. No. L, Room No. 17, Ground Floor B.E.S.T. Staff Quarters, Near Gandhi Hospital, Parel (East), Mumbai – 400012.

Phone No: 9768711665 / 9820738557

Other Hemophilia Treatment Centers:

Name: Sir JJ Hospital

Address: Byculla, Mumbai: 400008

Phone No: 022-23735555

Department: General OPD,

Monday to Saturday 09.30 am to 1.00 pm

OPD No. 26: For 1 to 12 year's old children

Medicine OPD No. 20: For 13 years and above

Name: Nair Hospital

Address: Room No. 403, 4th Floor, College Bldg.

OPD Time: 01.00 pm to 03.00 pm Every Monday

Name: Sion Hospital

Address: New Bldg., 1st Floor, Pediatric Department

OPD Time: Tuesday & Friday 08.00 am to 11.00 pm for Children, Monday 09.00 am to 01.50 pm

Hemophilia Federation (India):

Address: A-128, Mohammadpur (Behind Bhikaji Cama Place), New Delhi-110 066.

Phone No: 011-26174020 / 26175791

Email: ceo@hemophilia.in

Website: www.hemophilia.in

We sincerely thank you all for helping us / our Hemophiliacs to survive and live healthy life.

Institutions / Trust:

Aamada Trust
Akkalkot Swami Samarth
Al. Hamd Hospital And Medical Research Foundation
Baroda Pakaging
Baxter India Pvt. Ltd.
Cockpit Travels
Dattani Construction's
Dorabji Tata Trust
Dr. Chandulal Lallubhai Charitable Trust
Dr. Earl Gagan Jyot
Euro Foundation
Frigsales (India) LTD
Gala Trust
Haji Haroon Siddick Charitabal Trust
Indian Council of Medical Research
Jaffer Suleman Musafirkhana Trust
Jivan Jyot Drug Bank - Majuben Vora
Kansai Nerolac Paints Ltd.
Kedrion SPA (Italy)
Khair-e-Ummat Trust
Khidmat Charitable Trust
Kolsa Mohalla Halai Memon Jamal (Medical Center)
Lalbag Cha Raja
Laureen Kelly Communication (USA)
Lodge Perseverance No.338 S.C.Bombay
Mahalaxmi Mandir Trust

Malharbai Foundation
Marico Ltd.
Modern Educational Social & Cultural Organization (MESCO)
N. M. Wadia Trust
Novo Nordisk India Pvt.Ltd.
Orian Cormerx Pvt. Ltd.
Pamarox Pvt. Ltd.
Rabia Abdul Kader Millwala Trust
Rangoonwala Foundation
Sahara Educational & Medical Charitable Organization
Sahayata Trust
Salaman Khan Trust
Shri Jawahar Nagar Jain Shwetambar Murty Pujak Sangh
Shri Kailash Sagar Suri Foundation
Shri Narandas Dhanji Dharamsi Wadi Trust
Shri Sai Baba Charitable Trust
Shri Sidhivinayak Mandir Trust
Shri Swami Samarth Maharaj Trust Math
Sirsat Foundation
St. Maichal Chruch
State Blood Transfusion Council - Maharashtra
Suketu H. Nanavati / Jyoti S. Nanavati
Tarapur Trust
Uddan Trust
Valentine Charitable Trust
World Federation of Hemophilia (wfh.org)

Individuals:

Mr. Bhupendra Patel
Mr. Dilip Borade
Mr. Himanshu Joshi
Mr. Jay Joshi
Mr. Jagjivan L Thakkar
Mr. Kalpesh Joshi
Mr. Kishore Kotecha
Mr. Krunal Bhatt
Ms. Lakhvindherr Kaur (UK)
Ms. Laurie Kelley (USA)
Mr. Meet Joshi
Mr. Mehul Patel
Ms. Neena Shah
Mr. Noorbhai Sevvala
Mr. Rajiv Chhajer
Mr. Rajkumar Kalwani
Mr. Shyam Khatri
Ms. Sona Rupawala
Ms. Usha Parthasarathy
Ms. Jumana Colombowala

Doctors:

Dr. Alison Worsley (UK)
Dr. Arun
Dr. Aruna
Dr. Chandrakala
Dr. Chandran
Dr. Digish Doshi
Dr. Farah Jijina
Dr. Girish Chaudhary
Dr. J. K. Maniyar
Dr. Jayashree Kale
Dr. K. Ghosh
Dr. Khandale
Dr. Kinjal
Dr. Kirti Patil
Dr. Mallikarjun
Dr. Mamta Manglani
Dr. Manisha Madkar
Dr. Mehul Mehta
Dr. S. S. Mohanti
Dr. Narendra Bhatt
Dr. Rajeev Mahajan
Dr. Ramila Sanghavi
Dr. Sanjay Jadhav
Dr. Sanyal
Dr. Sapana Mishra
Dr. Sharma
Dr. Shishir
Dr. Shrimati Shetty
Dr. Tina
Dr. Usha Mathew
Dr. Vrinda Kulkarni
Dr. Vrushali

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Hemophilia Society Mumbai (Chapter)

Affiliated to Hemophilia Federation (India)

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Care Center / Admin Office : 205, Sai Apt, 64-B, Swarajya Bhavan CHS., Bhagwan Rao Parelkar Marg, Parel Village, Mumbai - 400012. **Phone :** 022-24158315 / 24184071. **E-mail :** mumbai@hemophilia.in