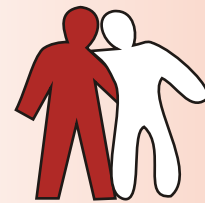


Hemophilia News



A Hemophilia Federation (India) Quarterly | AGM Special Edition | July-September 2010

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Cover Story: Annual General Meeting 2010

Many forward decisions, new ventures, and a brand new Executive Committee for HFI

The new Executive Committee of Hemophilia Federation (India):

Senior Management

President
Dr Kanjaksha Ghosh
VP Medical
Dr Cecil Ross
VP Development
Mr Vikash Goel
VP Finance
Mr H.M. Shreedhar Rao

EC Members

Ambrishkant Saxena
E. Raghunandan
Kiran Avashia
Kumar Shailendra
Rashid Lilani
Dr Sudhir Kulkarni
Vinay Manchanda

Youth Representative
Premroop Alva

Ex-Officio Members

Dr Alok Srivastava
Rtn Wg Cdr (Rtd) S S Roychoudhury

Message from the President



Dear PWH friends, Chapter Key persons, staffs of HFI and its chapters and well wishers of HFI and hemophilia care in India.

I have taken over as the President of HFI from the afternoon of 26.09.2010. Executive committee and the Vice President for different areas were also elected on that date in the AGM at New Delhi between 24-26 September 2010. Over the years HFI has made slow but steady progress in involving various state governments in haemophilia care in addition to its usual role in progressing the cause of PWH.

While being President of such an organization is a great honour, I also understand the responsibility which is attached to it. With all humility I would like to request you all to help me any way you can to achieve the vision of HFI as much as possible during my term in the office.

Only President of HFI or Executive Committee will not be able to do the job as effectively as when all of you lend a helping hand to the cause. Please advise us, suggest us and if any of you have any particular proposal please write to our CEO Wg Cdr Roychoudhury at HFI. Without your all round help and co-operation nothing of substance can be achieved. I am open to all your suggestions and criticisms.

With my best wishes to you all,
With regards,

Dr. Kanjaksha Ghosh



The 27th Annual General Meeting of Hemophilia Federation (India) was held at Viswa Yuvak Kendra, New Delhi from September 24-26.

The Senior Management team comprising President, Dr Suresh Hanagavadi; VP - Medical, Dr Kanjaksha Ghosh; VP - Development, Dr Devila Sahu; VP - Finance, G Subramanian; and CEO, Rtn Wg Cdr (Retd) SS Roychoudhury deliberated upon the growth of the organization over these years, and reflected upon how to move with a sustained growth towards HFI's vision of Hemophilia without disability, Children free of pain.

Various important concerns were discussed such as Importance of Lobbying and Advocacy with Governments and other agencies, with reference to HFI's overall growth in recent years and its present situation. Performance of various projects namely SAC, SOL, HEAT, HAC; Factor Availability, Accessibility and so on were discussed.

Cont. on pg. 2



Another AGM, another Elections
Kunnamkulam Chapter also conducts
Annual General Body Meeting

Wg Cdr Roychoudhury emphasized upon Communication and Resource Mobilization as he announced the approval of 35AC status to HFI, and its management. Many other issues of importance were brainstormed, decided upon, and taken forward.

The Elections of the EC was also held. Dr Kanjaksha Ghosh was elected the new President of HFI. A new Senior Management team, and Executive Committee were set up too.

Special guests Mr A B Chakraborty of ONGC and Lauren Kelly from Kelly Communications, who is a great friend of Hemophilia in India were present at the occasion.

The AGM saw representation of staff from entire country, and hence provided a useful platform to discuss issues of common as well as individual concern.

Like HFI, the Annual General Body Meeting and General Elections of Hemophilia Society, Kunnamkulam Chapter, too, were held at Kunnamkulam and attended by 192 members including PwH and their families and social activists.

The meeting was inaugurated by Dr K Aravindakshan, a well known literary figure in Malayalam, Secretary of the Pain & Palliative Care Society, Thrissur and an intellectual on Gandhian Studies. The meeting began with a prayer for the souls of the departed members of the Society including Kannan, son of Mr E Raghunandan and Rema; and Nikhil, son of Mr Vikash Goel who is a great friend of Kunnamkulam Chapter.

Dr Aravindakshan in his inaugural address condemned the insensitivity of the Government of Kerala for not realizing the right of the PwH to *Live with Dignity* as envisaged in the various international Human

Rights Declarations, Conventions and Covenants, and the article 21 of the Constitution. He demanded that Children with Hemophilia should be included under the 'Thalolum' project which offers free treatment for all children below eighteen years.

The gathering was emotionally charged as mothers of CwH began to narrate the medical, social and cultural problems they face because their children have Hemophilia. Many mothers broke down, Rema had a tough time. She listened to them and offered counseling.

Prof Gokul Das NN, E Raghunandan and Firoze were elected as President, Secretary and Treasurer respectively. The meeting congratulated Raghunandan who was also elected as an EC member of HFI. A team of mothers were constituted to meet the authorities of the Government Medical College, Thrissur to explore the possibility of developing a treatment center.

Young voices on Hemophilia in India
NHFYI Motivational Camp in Bangalore

A Youth Motivational Camp was organized under *Young Voices on Hemophilia in India* on 27th June 2010 at Bangalore. Youth Group Representatives from all the Chapters of Southern region participated in the meeting.

Regional Secretary Premroop Alva welcomed the participants and briefed about Camp's objectives and expectations. Youth Groups from Chapters had a detailed discussion on value-systems, giving reference to activities conducted at their ends.

Dhawal Bhanushali spoke on the importance of the value-system and discussed Youth Manual of NHFYI and its usage. Following this, a copy of the manual was distributed among the participants. A brief discussion was conducted by Dharmendra and Alva. It emphasized on the role of good leadership in carrying out Chapter activities. A demonstration on Self Infusion was given by Karthik Vijay and Sudev in a detailed step-by-step manner.

Alva talked in detail of a Common Activity Plan for NHFYI. Some of the salient features suggested by him included: *Formation of a formal structure in the Youth Group; Formation of a Core Committee in the the Group (for example, installation of a Convenor and a Treasurer); Discussion about the roles and activities of leaders and members of the Group; Creating brotherhood among young PwH and getting actively involved in Chapter activities; To discuss about the activities being held in other Chapters, the role of Youth group; Discussion regarding the forthcoming youth Regional Camp - Focus of the youth - Vocational training, Educational Sponsorship); and a walkthrough on HFI.*

Vikash Goel took the team through a presentation on the organization structure of HFI, NHFYI's parent organization. He shared about HFI's management governance and activities. He spoke in detail about the role the Youth have to play towards Chapters and HFI, and cleared the queries from the participants about HFI.

The participants learnt a lot from each other, different Chapters' ways of working and the challenges faced by them. They interacted very well and came up with a lot of ideas which they could implement at the level of their respective Chapters.

The fact that PwH themselves were conducting the workshop helped them interact more freely and openly.

Most of the problems faced by certain members were already tackled by others. Overall, the participants were extremely motivated towards spending more time towards the Hemophilia movement by organizing an active Youth Team in their Chapters and they were also keen in conducting regular meetings.



Immunization
Camp at Bhopal

Hemophilia Society, Bhopal Chapter organized an immunization camp against Hepatitis for PwH. The camp was organized in collaboration with the Department of Medicine and Gastroenterology, Gandhi Medical College, Bhopal.

The screening results were all negative for Hepatitis B. However, two PwH tested positive for Hepatitis C. The patients tested were given vaccination for Hepatitis B.

An Awareness programme on Hepatitis was also organized to discuss various issues on Hemophilia and Hepatitis. This was facilitated by a panel of experts, which included by Dr NP Mishra, Dr RK Jain and Dr VK Sharma Mr Thakur.

The treasurer of Bhopal Chapter discussed his experiences of his recent bleeding episode.

CME Camps and much more at Rajkot

After inauguration of a new Care Center for Hemophilia with support of Ashok Gondhia Memorial Trust in last quarter, Hemophilia Society, Rajkot Chapter organized a variety of activities and events for their PwH during the period June to August.

These activities included a Youth Group Meet on June 20, a Press Meet on July 18 and a Women's Group Meet on August 15. More than 120 PwH from the Chapter benefitted from the Physiotherapy and Homeopathy camps organized on all the three days. On June 20, Mr Krishnan from Chennai came

to observe activities of SOL and personally met PwH and their families. He selected 25 PwH for scholarships after spending sometime with the Chapter. Impressed by the activities, he announced a scholarship of US\$20 per PwH per month starting from January 2011.

Physiotherapists and Lab Technicians from the Chapter attended the training workshop on Comprehensive Hemophilia Care held at KEM Hospital, Mumbai on June 18.

The Chapter also held the Regional Council Meeting on June 27, which was attended by



around 15 representatives from the Western region.

We lost our two Friends

Nikhil, S/o Vikash Goel died on Sept. 27



Nikhil with his sister Rhea in happier times

Kannan was born with Hemophilia to Raghunandan (Kunnamkulam Chapter Key Person, EC Member and a senior worker of BJP Kerala State Unit) and Rema (advocate, and an active supporter of Hemophilia) in a middle-class family of Kunnamkulam.



Kannan, S/o E Raghunandan died on Apr 10

A bright student, Kannan, although not regular with classes due to obvious reasons, was a final year BA (History) Honors and held a Diploma in Animation.

Seeing his parents' active involvement in politics, Kannan also got fascinated with the same, and was elevated to the Youth Team of District Committee. He founded the *Kurukshetra Club* with fellows, an active organization in the field of Social activities.

The family, including Rema who holds a Masters degree in Psychotherapy and Hypnotherapy, took the task of forming Kunnamkulam Chapter to support PwH in the state of Kerala.

Kunnamkula Chapter is doing very well! Much credit goes to Kannan and his vision.

Updates from **Mumbai** Chapter

AGM: Hemophilia Society, Mumbai Chapter organized its 18th AGM on September 19 at Parel, 167 members attended the AGM. An informative Occupational Therapy session was also held by Dr Kitri Kene.

Balshiram Gadhave informed the members about the activities that were undertaken by the Chapter over the year, highlighting the World Hemophilia Day celebrations and the proposals sent to the Government of Maharashtra and BMC.

President Indira Nair requested the members to encourage their children to study well against all odds. Girishbhai Joshi, Vice President requested the members to try alternative remedies of Homeopathy and Ayurveda. Asha Gupta, Camp Director spoke about the activities and the future camp being organized by the Society. Dr Ashok Thakre from Dhule emphasized upon the importance of exercise and yoga.

Subhash Chikane, Joint Secretary gave all the information about ONGC project, SOL project and SAC projects.

SOL Meeting: Lauren Kelley, Usha Parthasarathy, Indira Nair and Balshiram Gadhave visited the homes of SOL members Yatish Patali and Javed Ansari on October 8. Lauren was impressed that in spite of staying in a slum area, these boys are studying hard, fighting against all odds to become successful. 22 SOL members and their families attended the meeting.

Special guests, Lauren Kelley and Usha Parthasarathy were greeted by the members. Lauren distributed the SOL amount to the members and requested the members to write

to the donors, as the donors are keen to know how the members are progressing.

The mothers expressed their concerns about the difficulties in raising children with Hemophilia. They expressed gratitude that the SOL money brings some happy moments in the lives of Hemophiliacs.

Government Lobbying: Persistent follow-ups on the proposal to the Government for providing free treatment to PwH by Gadhave, finally resulted in an invitation for a meeting on October 18 with Hon'ble Health Minister Suresh Shetty at Mantralaya.

The outcomes are bright and Dr Kanjaksha Ghosh will shortly have another meeting with the Government.

Milestone: Mumbai Chapter along with Aurangabad Chapter organized a National camp, *Milestone 2010* at Aurangabad. Around 66 PwH from different parts of the country participated in the camp. Dr Alision, her daughter Clare, and Lakhbir Kaur from UK were the guests of honor.



A Well-wisher Speaks

HFI happened to me some 15 months ago when Wg Cdr Roychoudhury randomly called me up, just to see if I was willing and available to do a publication. Sure enough, the very thought that the job would require writing, photography and designing, made me say yes.

What happened then last August was just the beginning. I did HFI's Annual Report and thankfully, the Management liked it. From then on, I was on! Being still in college would certainly mean a few adjustments, but I loved being on the job. In no time, I discovered how relevant an organization HFI were, and how important a contribution every word I pen down or every photograph I click, would be. HFI treated me well, I grew up learning a lot of things, and the association continues even today, when I work elsewhere.

For being a wonderful place to work at, and for serving such noble cause, HFI and its people - not just based in HO, but throughout the country and supporters from outside - will always be in my prayers and cares.

With my whatever little capacities - many of which are gifted by you only - I will sincerely try to do whatever I can to do my noble bit, for my blood brothers out there.

*Love and luck
Rishi Vashistha | Friend and well-wisher*

A boy with **Hemophilia** writes to his mummy Mom, too, shares her experience of bringing him up

To ..
Mummy

To me this one word 'Mom' means power, strength, faith, fighting spirit all combined into one.

There was a time in my life when passing SSC seemed to be a distant dream, infact an impossible task. Frequent bleeds throughout my body made me cry all night. Missing exams was a different trauma altogether. Yet you didn't lose hope on me. You didn't bow down to any pressure. Trusted your own blood, which paid off eventually.

I graduated with flying colours and then again was clueless as to what to do with my career. Ajay as promised to you, guided me to do MBA. Luckily for me I cleared the entrance and Ajay made sure I got the admission. Today here I am thanking you and the whole family for trusting me. With your blessings I became an MBA today. Passed my last semester with 66%. stood first class throughout the three semesters.

From the bottom of my heart thanking you again.

Your Son (MBA)
Vinay
28/6/2010



I was delighted to see my second son when the nurse brought him to me. I had a normal delivery with no problems. We happily saw him growing like a normal child, started crawling at six months. That is when I noticed a blue patch near his ankle joint, took him to the hospital. The doctor suggested me to take him to Bombay Hospital for doing certain blood tests. The doctor revealed that he is suffering from Hemophilia. What is Hemophilia?

We never knew what Hemophilia was, as nobody in my family was a Hemophilic. Dr Sunil Parekh, the Hematologist suggested that we should be careful taking care of this child. Luckily he didn't have major problems till the age of seven.

When he was eight, he got bleed in thigh muscles. His thigh had become like a log of wood. He was in so much pain that taking him to KEM hospital was a big task, right from putting him into the cab to putting him on the

bed. The visit to the hospitals and treatment with cryoprecipitate started. Later on we learnt about factor replacement through the doctors. Unfortunately he became Inhibitor positive at the age of eight and the bleeding episodes increased. We came to know about Hemophilia Society. I was encouraged to be a member of the Society in 1997.

Due to my active involvement with the Society, my knowledge on Hemophilia increased. Managing my child with the excellent support of the Society under the guidance of Dr K Ghosh, Dr Farah, Dr J Kale and Dr Devila Sahu helped me to treat my child better. Gradually I started getting involved more and more in the society activities, right from writing the minutes of meeting to making annual reports.

I started visiting Hemophilia patients in the hospital and listening to their problems. Wherever I could be of any help, I tried helping them like giving guidance, psycho-social treatment etc. In the process, I realized that

apart from my child, there were many other PWH children who needed proper guidance and support. I got myself involved in organizing the camp activities. The satisfactions that I got from doing all these activities cannot be explained.

Coming back to my son, hardly he attended his school from fifth to ninth standard as he used to bleed very often. He lost his father at the age of 13 and the major responsibility of looking after 2 sons, their studies and managing bleeding episodes of Vinay was a great challenge.

There was a time when we used to think that he will not be able to complete his schooling too and we were compelled to look out for options of correspondence course. But then we thought by doing that, he would be deprived of the basic luxury of meeting his school/college friends. So, we tried to convince his principal and teachers and they allowed him to continue his education despite his absence in the school.

But the things had changed. He graduated in Commerce with First Class and got himself rolled for MBA. The day which I cannot forget - as usual, I reached home from the office at 7pm on 28th June 2010 that is when Vinay handed over a letter to me and asked me to read it aloud.

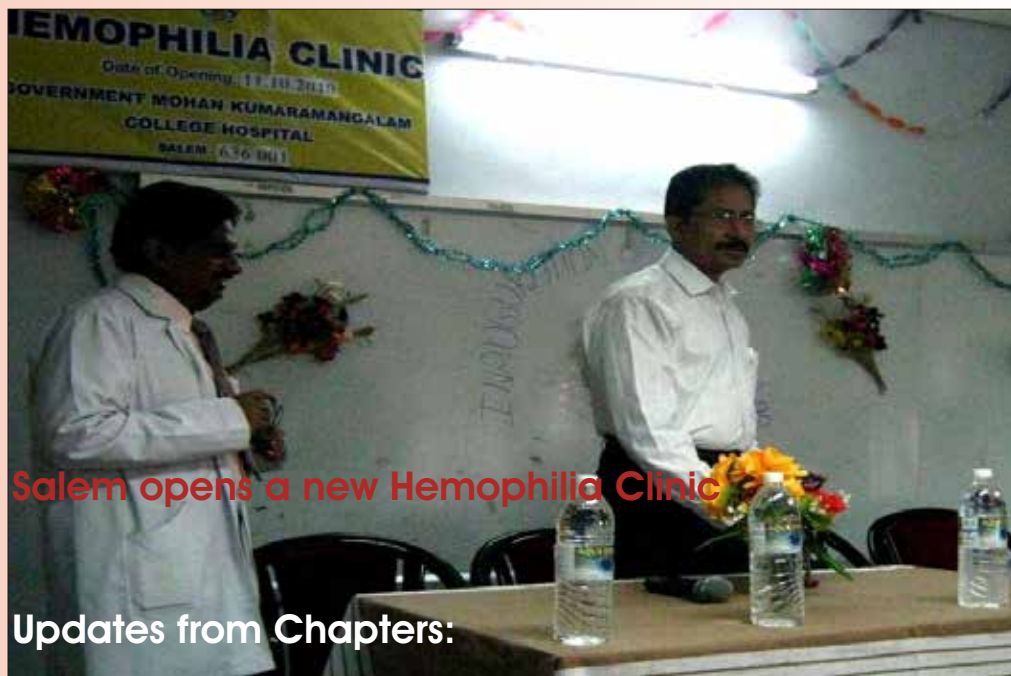
When I was reaching the end, I just could not read it aloud, my eyes were filled with tears of joy and satisfaction. I could not believe that my son had completed MBA in Finance with a first class, which I had never imagined. This was all possible with the great support from my elder son Ajay and my sis-in-law. I must have read this letter a hundred times because of the emotions that was stored in it. I can say this is the best letter/certificate that I received in my life. We celebrated his success by cutting a cake.

As a mother, it has been a long journey and a very difficult phase of life, when one's children can't attend school/college or go for outings. There is a lesson that I learnt during this entire journey - **Never Lose Hope, be positive and determined.** This will help us in building a good future for our children.

Forming Ladies Groups can be a great support system to children as well as to each other. These types of meets can encourage us to do better, lots of ideas get exchanged which are helpful. The feeling of "why this has happened to me" and the loneliness slowly goes away.

Last but not the least; it is sheer hard work, determination and the will to make HSMC succeed in the noble cause all along against all odds that has kept me going

Indira Nair
Hemophilia Society, Mumbai Chapter



Salem opens a new Hemophilia Clinic

Updates from Chapters:

Hemophilia Society, Salem Chapter opened up a new Hemophilia Clinic at the Government Mohan Kumaramangalam Medical College and Hospital. The opening ceremony was held on October 11 in presence of Chapter staff, PwH and families, and guests.

Hemophilia Society, Coimbatore Chapter conducted EC Meetings in July and August, and subsequently held its AGM on September 5 in Perur.

The Annual and Audit reports were shared by the Secretary and Treasurer respectively and passed in the forum. Shantimala explained the allotment of budget for factors by Tamil Nadu Government, and how to get registered with the hospitals.

Novo Nordisk organized an inhibitor screening programme for the Chapter and 83 patients benefitted from it. SOL payments for the quarter were disbursed.

Hemophilia Society, Hyderabad Chapter also organized its AGM on August 22 at Sweekar Upkar Foundation. Doctors from NIMs made it extremely successful and beneficial with a PowerPoint presentation on *Genetic Inheritance*.

Dr Pamela Narayan, Dr VR Srinivasan, Dr Krishna Prasad, Dr Mallikarjuna Setty, Dr Praveen and Dr Uppin participated in the Open Clinic and cleared many doubts of PwH. The doctors also sent out the message of being successful in getting factor support from Government, highlighting dedicated efforts of the Chapter.

They advised all PwH to approach their nearest district government civil hospitals to register and to get factor and treatment.



Rajkot Chapter PwH enjoying graceful and unique Garba (folk dance of Gujarat) during Navratri Celebration

Goa is the newest baby on HFI's board

HFI has successfully started a Chapter in Panjim, Goa. The Chapter has been formally inaugurated on October 24 by organizing a day's camp, attended by PwH and their families, doctors, media and well wishers. The treatment centre is located in Goa Medical College & Hospital.

HFI is grateful to Dr Jindal, Dr Mimi Silvera and staff of Goa Medical College and Hospital for their valuable support. Ms Manjit K Chohan and Dr Silvera will serve as the President and Vice President respectively.

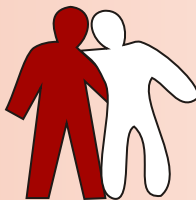
Dr Devila Sahu and Ms Lakhvir Kaur played a major role in formation of the Chapter. Vikash Goel, Rashid Lilani and Dr Sunil Lohade were also involved.

Hemophilia Society Madras Chapter conducted its AGM on July 18, about 82 pwhs and their family members participated the AGM. Ms Laureen Kelly, President SOL visited the chapter on July 27 and interacted with the beneficiaries and their family members. A physiotherapy clinic was held and 24 members benefitted from it. The chapter also held CME on September 20, which was attended by 125 doctors.

Hemophilia Society, Patna Chapter has two major reasons to be happy about. Firstly, the govt. of Bihar has included Hemophilia Awareness in their state health programme and has taken the responsibility of locating PwH as well. Secondly, Ultra Sound facilities is provided free of cost at Hemophilia Hospital, Patna for Hemophiliacs and their family members. The Chapter is grateful to the govt. of Bihar and specially to Shri Shatrughan Sinha, who is a great supporter of HFI.

Hemophilia Society, Pondicherry Chapter organized blood screening test on blood related diseases for PwH. Under guidance of physiotherapist Dr Nalini, Pondicherry Chapter held a swimming camp Murungampakkam. She discussed about the importance of physiotherapy for PwH and advised them to have Inhibitor Test done for their children on a concession payment at PIMS City Centre, Pondicherry. Following the programme, SOL scholarship payments were disbursed for the selected PwH where about 110 members were present.

We thank **Novo Nordisk** for sponsoring this edition of **Hemophilia News**. To advertise with HFI publications, get in touch now!



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