

Hemophilia News



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Cover Story
April 17: World Hemophilia Day
celebrated with energy
and enthusiasm

Remarkable Achievement in 27 years: HFI has been telephonically informed by the National Committee for Promotion of Social and Economic Welfare, Department of Revenue, Ministry of Finance, Government of India that our application for Award of giving 100% tax exemption under section **35AC** of Income Tax Act, 1961, has been approved. We are awaiting the Government Letter, which is expected in a month's time.

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World Hemophilia Day, April 17 gives us one distinguished moment to salute Frank Schnabel, the founder of World Federation of Hemophilia (WFH), for the outstanding contribution that he made to the Hemophilia fraternity world-over. Here, we also remember Ashok B Verma, the father of Hemophilia Movement in India and the founder of Hemophilia Federation (India) for his commendable, tireless work towards the cause of Hemophilia in India.

This year, WFH launched *The Many Faces of Bleeding Disorders: United to achieve Treatment for All* as the key theme for World Hemophilia Day. Taking cue from this; and towards the larger cause of Bleeding Disorders, Hemophilia Federation (India) and its Chapters conducted various activities for their respective beneficiaries across the country in all the four regions.

Guwahati Chapter: Hemophilia Society, Guwahati Chapter met Hon'ble Health Minister of Assam Dr Himanta Biswa Sarma and sought help of State Government. In continuation to this, the Chapter organized an Open Clinic on April 11 to observe World Hemophilia Day (due to already lined-up celebrations of Bihu, one of the main festivals of Assam) and invited the Minister to inaugurate the same. The Chapter also organized

press meets, Radio and TV awareness campaigns on and for a couple of days after the event to make a good noise on the day to sensitize Government officials (especially the Health Ministry). The local newspapers made a commendable mention of our efforts.

Patna Chapter: Hemophilia Society, Patna Chapter celebrated World Hemophilia Day by organizing a small programme at Income Tax Crossing, Patna. In the event, more than 200 girl children formed a Human Chain for Hemophilia to spread awareness about the cause and sensitize people. Hemophilia supporter and veteran actor Shatrughan Sinha sponsored special T-shirts for everyone. Nitish Kumar, Honorable Chief Minister of Bihar also passed by the Chain to encourage the children.

Delhi Chapter and HO: Hemophilia Society, Delhi Chapter along with Head Office celebrated World Hemophilia Day in a different way this year. With sponsorship from Baxter, a picnic was organized for around 150 CwH and their families at Splash Water Park at GT Karnal Road on the outskirts of Delhi. The exercise not only provided for a fun-promising and safe picnic for PwH, but also helped everyone beat Delhi's scorching heat with a day full of water-based activities.

A bouquet of contrasting activities organized throughout the country by HFI and Chapters to mark the **biggest day** of the year for the Hemophilia fraternity

The CwH were accompanied by HFI staff, Wg Cdr Roychoudhury (CEO); Dr Raman Khanna; Indira Venkataraman and Dr Garg; and representatives from Baxter.

Bangalore Chapter: Hemophilia Society, Bangalore Chapter celebrated by creating awareness. A role-play on Hemophilia was conducted with support of Nursing First Year students of St Johns Medical College and Hospital (SJMCH). The event, *Awareness of Hemophilia from People to People* recorded an attendance of more than 200 persons including medical students, nurses and general public. Dr Cecil Ross, Dr Fulhton and Dr Kurien of SJMCH shared their experiences in handling challenges related to Hemophilia. They also appealed to the participants to join hands with the Hemophilia Society in improving the lives of PwH.

Davangere Chapter: Hemophilia Society, Davangere Chapter organized a meet with Amaranarayan (District Commissioner) and appealed to him to give suitable directions to District Hospital authorities to ensure supply of AHF. Dr Hanagavadi also led a delegation to Sriramulu (Minister of Health and Family Welfare), BN Nayak (Health Commissioner) and Ramana Reddy (Principal Health Secretary) and sensitized them about the problems in government hospitals.

Chennai Chapter: Hemophilia Society, Chennai Chapter held a thanksgiving function for Tamil Nadu Government for announcing free treatment with Factor Concentrates to all PwH in Government Hospitals throughout the State in the Budget. This was attended by M Subramaniam (Mayor of Chennai), VK

Subburaj (Principal Secretary to Health and Family Welfare, Government of Tamil Nadu) and Dr Alok Srivastava. The Health Secretary reiterated that he will take up the concept of Comprehensive Care Centre with the Government.

Manipal Chapter: Hemophilia Society, Manipal Chapter organized a Kite Flying Festival to raise funds. The sale of kites with lucky coupons was inaugurated by the Pro-Chancellor of Manipal University. It was a spectacular site to have hundreds of kites in the sky. Volunteers and experts were available to help. A lucky draw was held. The prize of the lucky draw was INR 30,000. In another event called *Asha Kiran*, more than 130 PwH participated in a 2-day camp at EMHS High School, Manipal. The highlights of the camp included clay modeling sessions, clinics, interactive sessions, education on Hemophilia care, and picnic on the beach. The Chapter also had its AGM on the occasion.

Mumbai Chapter: Hemophilia Society, Mumbai Chapter organized a function with Suresh S Shetty (Hon'ble Minister of Public Health and Family Welfare, Government of Maharashtra) in the Chair. Medical Experts and doctors addressed queries of PwH and their families.

Rajkot Chapter: Hemophilia Society, Rajkot Chapter organized activities from April 16-18. A Physiotherapy and Occupational Therapy camp was held under the guidance of Dr Kirti Kenny and Dr Tina from Mumbai and trained therapists from Rajkot. A press meet was held on April 17, where Team Hemophilia addressed media. The Chapter



also inaugurated Ashok Gondhia Memorial Trust Hemophilia Care and Research Centre in presence of Dr VB Kathiria (Former MP and Minister of Health, Central Government). Dr Suresh Hanagavadi and Dr Devila Sahu; Rikhav Sanghvi (President, Lions Club Main Rajkot) and Chapter staff were present.

WHD Celebrations across the country have indeed strengthened HFI's integrity!

Photographs:

Cover: Young boys at Manipal Chapter learn to model clay at *Asha Kiran*, a 2-day Camp held at EMHS School, Manipal (Manipal Chapter)
 Top left: Human Chain for Hemophilia at Income Tax Office (Patna Chapter)
 Grid (from left) First row: Meeting with Dr Himanta Biswa Sarma, State Minister of Health (Guwahati Chapter), Picnic for CwH and families at Splash Water Park (Delhi Chapter and Head Office), Summer Camp on Hemophilia (Varanasi Chapter)
 Second row: World Hemophilia Day celebrations (Angamaly Chapter), Balloon launch to inaugurate the role play about Hemophilia (Bangalore Chapter), Thanksgiving ceremony in honor of Tamil Nadu Government for supporting Hemophilia (Chennai Chapter)
 Third row: Kite Flying Festival for CwH and families (Manipal Chapter), Conference in presence of Dr Suresh Shetty, State Minister of Health and Public Welfare to clear doubts about Hemophilia (Mumbai Chapter), Inauguration of new Care Center for Hemophilia with support of Ashok Gondhia Memorial Trust (Rajkot Chapter)

Project Updates:
Volkart Project
concludes with
success

Project **HEAT**
reaches out to
1000 CwH
Save One Life,
Sponsor a Child and
Hans Foundation
Projects do well



Volkart Project: Volkart Foundation and Hemophilia Federation (India) conceived a unique idea of extending care to PwH by strengthening Chapters. Thus, Volkart Project was born to support existing Chapters that are active at the community level, but were in a critical situation due to lack of funds and/or technical support. These Chapters (one from each region) were called Medium Grade III Chapters. Subsequently, Bhadrak, Bikaner, Karaikal and Surat were selected for carrying out activities under Volkart Project.

From July 2008 to June 2009, the first phase of Volkart Project did extremely well. It was extended for another year, and the second phase also concluded successfully. The total grant for 2 years was INR 26L.

During the course of the Project, the Chapters conducted many activities like Continuous Medical Education (CME) Camps, Women Group Meetings, Parent Meetings, Physiotherapy Camps for PwH, Prenatal Diagnosis Tests, Carrier Detection Tests and so on.



Volkart Project also offered Factor support to the selected Chapters while conducting Self-Infusion Training Camps. Doctors and physiotherapists from prestigious medical institutions across the country attended these Camps and Workshops and it was a learning experience to them and the beneficiaries as well.

ONGC-supported Project HEAT: Following strong lobbying and dedicated efforts towards the end of 2009, HFI launched the *Hemophiliacs Education and Transformation Project* with support from ONGC on January 18. The objective of HEAT is to educate 1000 CwH from poor families for 3 years. The total grant for the Project would be INR 33L for the first year.

Under HEAT, HFI successfully identified 1000 school-going CwH between 5 and 18 years of age and living below the poverty line, from across India and shared the same with ONGC. The first instalment of INR 11L has been disbursed to the respective beneficiaries to support their education. The Project is still nascent and HFI is hopeful of good results.

SOL/SAC: 315 CwH received support for education under Save One Life Project and 85 CwH received Factor support under Sponsor a Child Project.

Hans Foundation Project: With a grant of INR 12.61L for 2 years from Hans Foundation, HFI supported education of 50 CwH under SOL and provided Factor support to 25 CwH under SAC.

We extend heartfelt gratitude to all our supporters for contributing to our vision in various ways. Thank you!



My stint of working with HFI has been an eye-opener for me not only towards Hemophilia but also the grave situation of CwH in the society. I have become aware of the psycho-social impact of the disorder. Lifelong nature of Hemophilia makes children vulnerable to depression, helplessness and inadequacy and primary and persistent fear about their health slowly steals their childhood away. The situation becomes worse for families from lower socioeconomic strata, and irregular availability of Factors in hospitals also adds to the already burdened families.

HFI and its Chapters have been pioneers in the welfare of PwH in India. Through guidance and counseling, HFI not only empowers them for the present but also develops them into a means for spreading awareness. Project HEAT is a significant step towards helping educate CwH. In my experience, working for HEAT has made me realize that such initiatives are indispensable for BPL and marginal income families, as the treatment itself leaves less room for child's education. Congratulating and wishing good luck!

Akanksha Jayant
Delhi School of Social Work
Intern with Project HEAT

Young voice on Hemophilia in India

National Hemophilia Youth Federation of India (NHFYI)

National Hemophilia Youth Federation of India (NHFYI) (North Zone) conducted a Motivational Camp at Hotel the Golden Buddha, Sarnath on June 10. Representatives from Hemophilia Societies of Kanpur, Lucknow, Agra and Varanasi attended it.

The participants talked about their roles in their respective Chapter, the problems faced and how they handle them. Apart from a general good response, some participants shared their occasional inability of active participation because of health/finance issues. Some of them even talked about how their families are not too supportive of them for various reasons. They also discussed about leadership and what makes a good leader? Many of them defined the qualities of the leader, some of them gave their own

definitions, some tried to explain through examples and so on. They also talked about the major obstacles that kept them from becoming a strong leader and a Young Voice. Most of the participants rendered health-related issues to be one of the major reasons, followed by financial problems and inadequate family support. Later, a short lecture about the Hemophilia Federation (India) was delivered by Sandeep Pandey. He share why the organization exists, giving ample insight into history and the activities that HFI conducts for the care and welfare of PwH/CwH in India.

Chapter Secretary OP Pandey thanked the participants for coming. He urged them to move ahead enthusiastically so that other CwH may also be motivated for the same and join the society's activities actively.



Fund Distribution Programme at Varanasi

Varanasi Chapter held a fund distribution programme for the beneficiaries of SOL and HEAT projects on June 10. Chief Patron and Commissioner of Varanasi, Ajay K Upadhyay formally inaugurated the programme by lighting up the lamp and personally distributed funds to CwH

"This is indeed an enthusiastic programme that HFI/Chapters have initiated with ONGC", said Upadhyay as he praised the Chapter's activities and wished the project a grand success.

The Commissioner said that *Ashadeep*, Varanasi Chapter has been providing good facilities to the needy PwH of Purvanchal. He also, however, stressed upon the need to set up a Hemophilia Care Unit at National level, which can provide all the needed comprehensive care to all the persons with hemophilia across the country with rapid action with time frame.

Hemophilia Youth Camp at Coimbatore

Hemophilia Society, Coimbatore Chapter organized a Youth Camp from April 30 to May 2 at Kothagiri Hills of Nilagiri District. A group of around 40 young Hemophiliacs, (including 5 girls) were taken on the Camp. The participants introduced themselves to each other and conducted various indoor activities for the first day owing to downpour.

On the following day, the participants had a Hydrotherapy session in a heated swimming pool for about an hour. This was liked by everyone, especially the kids. The group made a quick visit to Conoor, Dolphin Nose and Katrina Falls. Towards the evening many fun

activities like Basketball and Throwball matches, and *Pass the Ball* were organized. Loads of fun and laughter echoed all through.

The next day was full of even greater fun with a game of *Bursting Balloon*. Everyone had five balloons tied to their backs, and the objective was to burst other people's balloons and save their own. Apart from these, *Treasure Hunt*, *Hemophilia Quiz* and many other activities were conducted followed by a detailed talk.

The Youth Camp empowered the participants with greater knowledge and confidence to live with Hemophilia. Everyone went back happy!

SOL Fundraising Programme held in New York

SOL Board of Directors, Tara Reddi and Laurie Kelly held a fundraising programme in New York. *Bollywood Chic* required the participants to dress up in Indian attires and was organized with an intent to support Indian beneficiaries under SOL. Indian food and Bollywood music were other features of the event.

Dr Ranjana Kulkarni of Nashik Chapter attended the event. People were encouraged to buy tickets, RSVP, and make a donation in the event which was held in the prestigious art studio of Hunt Slonem in New York.

"We are pleased to have with us Dr Ranjana Kulkarni. She is our program partner there, and has enrolled many children with Hemophilia in Save One Life", said Laurie Kelley. "All proceeds of the event will go towards our India program, where the bulk of our beneficiaries are located", she added.

Save One Life sponsors over 550 children in nine countries, giving them funding that is otherwise difficult for them to get. The funding received through SOL is used to transport children to clinic, to buy medicine, and to pay school fees.

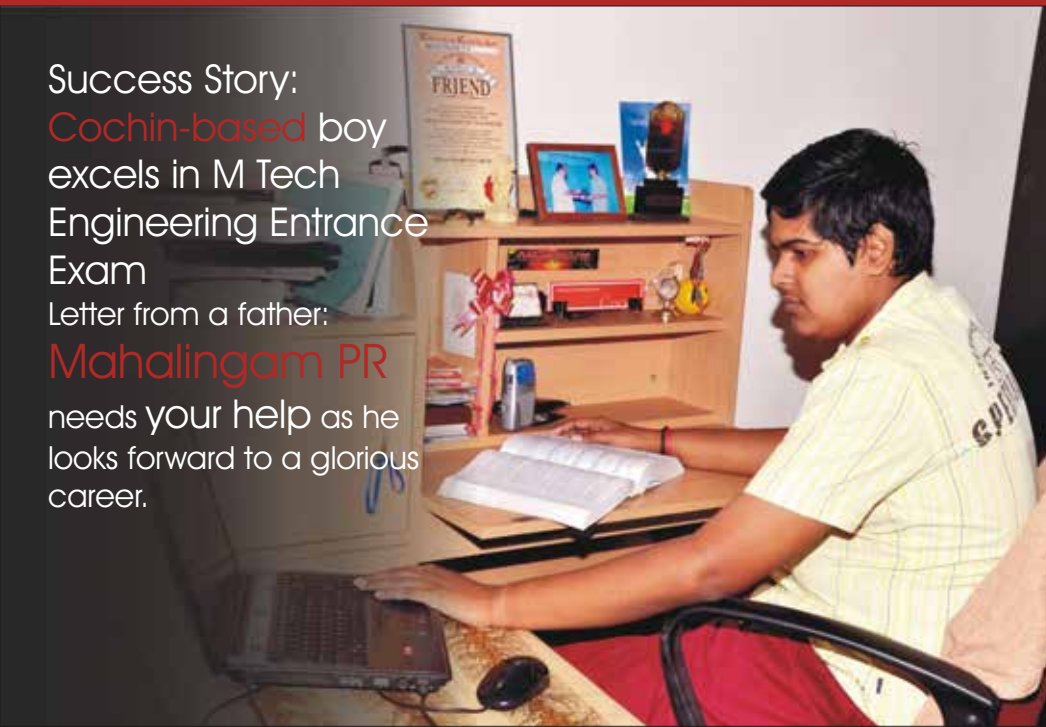


Hemophilia Federation (India) is thankful to SOL for being a strong support towards the care and welfare of CwH in India.

Success Story: Cochin-based boy excels in M Tech Engineering Entrance Exam

Letter from a father:

Mahalingam PR
needs your help as he
looks forward to a glorious
career.



At 21, soft-spoken Mahalingam PR from Cochin is nothing short of spectacular. From Grade 10, where he scored an aggregate of 95% marks, to date, where he has cracked the Graduate Aptitude Test in Engineering (GATE) with a percentile of 99.51% and an all India rank of 524, he has been an achiever! Earlier too, he scored an aggregate of 93% in +2, cracked the Government Entrance Examination for Engineering with an overall rank of 2179, and secured 83% in his Bachelors in Technology (Computer Science).

However, even with such encouraging figures to place on record, there is one thing that he needs to still conquer: Hemophilia! Here's a letter from his father Ramaswamy PM, who is both happy and worried at the same time for his young achiever:

Today is a very important day in our life. My son just finished his B Tech in Computer Science. He is now 21 and recently did well in GATE, which decides for any student who aspires to postgraduate in the field. The college where he just graduated (Rajagiri School of Engineering and Technology) offers M Tech in Computer Science and we are very

sure that he will certainly get admission to the course in which he has always been interested. Being severely Hemophilic (less than 1%), he has undergone so many issues from his young days and somehow with the grace of God he has reached this stage. I have spent huge amount of money (on an average, INR 35000 per month) for his treatment. Now I am 56 years, and just 2 years away from my retirement from a Private Limited Company.

Therefore, I seek your help towards sponsorship of his fees, which will be approximately INR 65000 every six months. There will be 4 semesters that Mahalingam needs to study in M Tech and he wants to take up teaching after that. Somehow I was able to push and pull till now but now I am old and need support. I would be grateful to hear from you.

PM Ramaswamy

A young boy needs your support! If there is anything you could offer to help Mahalingam, please get in touch with Hemophilia Federation (India). You can also contact PM Ramaswamy at cochin@hemophilia.in or call +919349315905.



Abilities Mela at Hyderabad

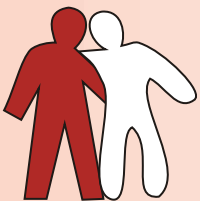
Hemophilia Society, Hyderabad Chapter participated in *Abilities Mela*, a 2-day event organized for *Persons with Disabilities*, and highlighted the cause of Hemophilia among the audience. The *Mela*, in its fourth year, organized on June 12 at Sweekar Upkar Complex in Secunderabad saw many people from all walks of life, come together to fight disability in its varied forms.

The programme was inaugurated by Indian Cricketer VVS Laxman. Many NGOs working for PwD took part in the Mela variously by making presentations, selling merchandise, putting up donation boxes and awareness stalls, thereby promoting the cause of Disability through collective efforts.

Hemophilia Society also put up a stall displaying the plight of Persons with Hemophilia (PwH) and showcased the Society's and HFI's work. "The *Abilities Mela* is actually a place where people get opportunities to showcase their skills, and be admired by the people who come here," said Laxman, who was impressed by the various talents that PwD displayed.

There was a good media coverage of the event and it provided for a platform to lobby with many top Corporates and the Government towards the cause of Hemophilia.

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



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