

Annual
REPORT
 2010-11



Hemophilia Federation (India)

“HEMOPHILIA WITHOUT DISABILITY, CHILDREN FREE OF PAIN”



OUR VISION

“Hemophilia without Disability, Children Free of Pain”

OUR MISSION

To locate undiagnosed “Persons with Hemophilia (PWH)”
To educate and provide proper information on Hemophilia
Care to both Persons with Hemophilia,
their families and the medical fraternity

To make treatment available at affordable cost

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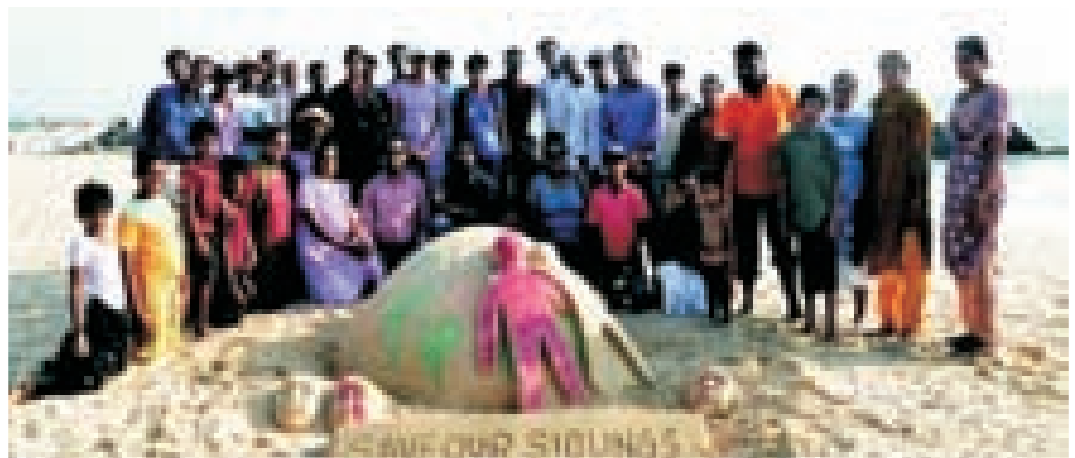
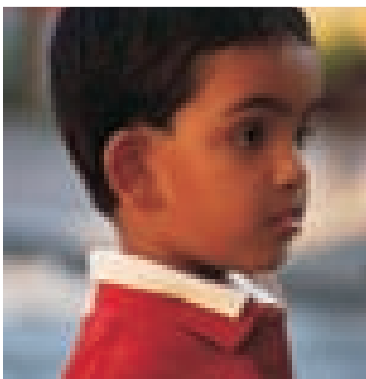
Website: www.hemophilia.in, www.hemophiliaregistry.in

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FROM THE PRESIDENT'S DESK



(Prof) Dr Kanjaksha Ghosh, MBBS (Hons), MD (Med),
DNB (Haem), MNAMS (Path), MRCP (UK),
MRCP (Ire), FRC Path (Lond), FAMS, FACP (USA), FICP, FNASc
President Hemophilia Federation (India)
Director, King Edward Memorial (KEM) Hospital, Mumbai

Dr Ghosh has been associated with hemophilia care for more than a decade. He has served as a Consultant in Comprehensive Hemophilia Care and guided programmes as the Director of National Institute of Immuno-haematology & member of Indian Council for Medical Research (ICMR), Delhi.

Dear Friends,

It gives me immense pleasure to present before you the activities of HFI in this event packed year. I would like to remind you that through various chapters HFI has reached in different areas of this country but this country is no ordinary country. Spread over more than half a million villages in 650 districts with average population of 2 million per district we have a long way to go. This year, after almost 5-6 years we have opened 3 new chapters in the country, they are Goa, Hubli-Dharward and Yamuna Nagar. Out of these three Goa is doing extremely good work. The PWHs in Goa are managed efficiently by well-trained doctors in a clean environment. They conducted within this short period 4 major operations & organized few CMEs.

National Haemophilia Training Centres: For quite sometime, it has been felt that we need more centres at National level which can contribute to the welfare of PWH and activities of HFI by way of improved management, training laboratory technicians, pathologists, physicians, paediatricians, dentists, orthopaedic surgeons and physiotherapists for optimum haemophilia care suitable for our country. In a recent meeting we have chosen initially 3 such centres (1) AIIMS, New Delhi (ii) St. John's Medical College, Bangalore (iii) Institute of Haematology and Transfusion Medicine in Kolkata. In addition to above activities, these institutes will also organize local and regional level CME in collaboration with HFI and local chapters. They will also take active part in advocacy for PWH with local and Governmental agencies.

Communication: Our newsletters are being published regularly. We have recently improved the appearance of news letter, increased the number of pages and our communication department has already requested chapter key persons to write brief history and functioning of each of the chapters. We will schedule publication of these articles after editorial correction and once majority of the chapters have contributed we will collate them and publish the work as a book annotating the history of development of haemophilia care in India. Newsletter also accepts life sketch and struggle of successful PWH, account of important medical management of a patient in the chapter, news of formation of various groups (Ladies group, Youth group) results of advocacy programme etc.

Increased Usage of Factor Concentrates: There has been substantial increase in usage of factor concentrates by PWH in India in the last 2 years. This year approximately 60 million units of factor concentrates have been used by our @14,000 PWH. This works out at 4.500 I.U. factor concentrate usage/PWH. I am sure this is some sort of a record for this country and is only possible because of HFI's untiring effort in involving various organizations for haemophilia care. Kedrion has provided 1 million unit of free factor IX through the good office of Laureen Kelly and Ms. Usha Parthasarathy. This product was successfully distributed to all the chapters of HFI and helped many of our PWH. Similarly WFH has donated @ 7.5 million units of factor VIII concentrate for donation to doctors at various chapters. This is a recombinant product and the donations have now been completed. WFH also provided substantial amount of factor concentrates to CMC Vellore and to my Institute for conducting surgery in PWH. I have already provided factor concentrates from NIIH quota to atleast 10 patients who needed various operations or had life threatening bleed. One of the areas of concern is that we do not have

FEIBA or Novoseven at affordable prices or as a free product for patients with inhibitors. However, these products are available on payment at cost/subsidised prices.

Homeopathic Management of PWH: While there could be lot of debate on whether homeopathy is a science, whether it is only a placebo effect or whether it has after all some substance in it which we do not understand. However, I am given to understand that many patients have got substantial relief while on homeopathic management. Homeopathic management is cheap and one can continue management with factor concentrates while on homeopathic medicines. Being a cheap form of treatment this could be a rallying point in small places where small PWH groups could meet. Dr. Kundu from Nashik claims some strikingly good results on homeopathic management and some of his patients have endorsed his views. Some other chapters of HFI have also introduced an additional limb of haemophilia management through homeopathic medicine.

Visit of WFH President: President of WFH with his team is likely to visit India sometime in October this year. His visit has already been fixed by WFH. He will interact with few chapters on his way & his main interaction will be with HFI executives and with various Govt. bodies to facilitate better care for PWH in India.

Corporate Involvement in HFI activities: For a long time the only corporate body which helped PWH and HFI is a Pharmaceutical Company. It was understood that unless various corporates in India extend their help, it will be very difficult for HFI to survive, particularly when the care of PWH will be totally handled by Govt of the states in future. At that time HFI will be totally out of 'Factor concentrate distribution' and its attendant financial help. However, for last 5-6 years, it appeared to be an impossible task to mobilize many corporates towards helping the PWH in this country. This year particularly due to active engagement of present "CEO" supported by the dynamic EC and administration, ONGC has come in a big way to help CWH in India for educational support. Similarly, help is regularly coming through Save One Life-USA, Save A Child-UK, programmes. SAIL has also extended some financial help and the help from Baxter and NovoNordisk is also gratefully acknowledged. Volkart Foundation has been supporting HFI for last 3 years in the development of few chapters. The Hans Foundation also has been supporting HFI for last year through treatment and education support to CWH.

National Haemophilia Registry: The work on National Haemophilia Registry is progressing well. Baxter India has augmented its funding to improve the performance of this registry. All the chapters have received their passwords and members from NHR team will reach various chapters to physically verify the data. I would like to thank Mr. Somu of Tattwa Software, Premroop Alva of youth group, our VP development and VP Medical for actively taking interest in this project. I must reiterate that NHR is everybody's responsibility. If chapters do not update their data regularly on NHR, the NHR will remain unutilized. NHR has many useful applications for lobbying for raising funds to provide vital statistics about our PWH management. Hence, my earnest request to all chapter key persons is to see that NHR data is regularly uploaded in the site so that each of the chapters remain uptodate as to their PWH statistics are concerned.

Relief of Income Tax under 35AC: We all know that Govt. of India has accorded this income tax benefit (100% exemption) to donors of HFI this year. I request all the chapters to use this facility and actively get the donations. The rule of 35 AC stipulates that unless the organization raises the amount sanctioned to it, the receiving organization will be penalized for non compliance and will forfeit the benefit. Hence it is my earnest request to all the chapters to be active in fund raising under this head.

Financial Health of HFI: After a long time, the financial health of HFI looks better in the face of falling financial margin from factor concentrate servicing by the organisation. I cannot say the organization is in the pink of financial health as yet but a turnaround seems to have taken place. As a result of this positive development, a series of activities to help PWH this year has been budgeted for by HFI. This also will be discussed by our VP finance and CEO.

Areas of concern: There are several areas of concern and if we would like to progress, we have to answer those concerns effectively. We must not forget that captain of a team can do lot more if each of the player helps and he/she can do precious little if other players consider that captain is there to do and we are here to see what happens. Haemophilia Federation of (India) is your organization. It is you, the dear PWH and their families who can bring this organization to a lofty summit where you want to be by helping each of the chapters and HFI as follows:

(i) Please spread awareness about haemophilia as much as you can, i.e. in your organization in your locality,

and with any body you meet.

- (ii) Try to raise as much fund as possible & route it through HFI so that the donor gets all the benefit of 35AC.
- (iii) Please do not bother how much HFI is getting out of it because HFI is also doing a lot for you. HFI is there for you & I am sure that whole organization grows out as a healthy organization if we are together.
- (iv) For many of the benefits that HFI and its chapters are trying to get for you, why is it that your signature, photographs etc. are not available in times of need. Many of you are not contactable hence please give right email and right addresses.
- (v) Don't ever give up. Haemophilia is compatible with good education; good life provided you are steady fast in your resolve that you will overcome all the odds. In fact, we all have to face the life with the challenge of haemophilia care.
- (vi) Attending as many meetings of your society/chapter as you can. This improves your bondage as well as resolve to go further and take the society further.
- (vii) Try to forge relationship with like minded NGOs.
- (viii) Contact your Councilor/MLA/MP. Now a days they have lot of funds for local area development.
- (ix) Once the central and the state govt. start giving assistance to PWH all over the country we should be ready to accept it and make equitable distribution through all the 650 districts of India by remaining attached with chapters and district level groups.
- (x) Presently there are lots of different benefit schemes for students by various governmental and private organisations and each of our PWH student should try to access them.
- (xi) Whatever success you have achieved please communicate them to your fellow PWH for encouraging them. "Haemophilia Newsletter" from HFI is hungry to publish these accounts of success and struggles of our PWH friends which brings joy, sense of achievement and encouragement to all.
- (xii) Finally, have the quintessential motto of India "Move onward March forward".

Road Ahead: This year with your help and hard work done at HFI headquarter by our CEO and his team, for the first time HFI has received funds for PWH Welfare which was generated by fund raising. Servicing of factor concentrates slowly turning out to be of secondary importance to HFI as it was envisaged 5 years back. Due to the continued efforts at HFI and its contingent chapters already 15 states in this country have started giving some assistance to PWH.

Our NHR will be fully functional in another few months time. As we develop full fledged NHR our ability to negotiate with Govt. and other organizations will increase further. Central Govt. is already toying with the idea of putting Haemophilia/Sickle Cell Anaemia and Thalassemia management and control in 125 year plan document. Major Central Govt. organizations like Employees of Central Govt., Army, Railways, Govt. Navratna/Maha ratna companies. ESI beneficiaries are already getting all the benefits for PWH. This has only been possible through last 10 years struggle by HFI and its chapters. Meanwhile more and more Universities are opening Post graduate training programmes for haematology. HFI is also conducting many workshops and training programmes to develop manpower for the care of PWH. All these are good news for PWH in this country. In coming years rest of the states will join hands with HFI and its chapters to care for PWH and we will develop many more programmes for PWH in the country.

Finally inspite of the efforts by all of us we could not save the lives of several PWH in the country, they passed away in the prime of their lives for no fault of theirs. While we mourn the loss of their parents and pray to God almighty for their souls to rest in peace. Let us also take the pledge that we will continue our struggle for proper management of PWH in this country as this only can be a final tribute to the departed souls.

I with my EC members thank you all for giving us the opportunity to work for this splendid organization. JAI HIND!



(Prof) Dr Kanjaksha Ghosh

FROM THE VP MEDICAL'S DESK



Dr Cecil Ross, MBBS, MD General Medicine

Dr Cecil Ross is a Professor of Medicine and Head Unit I and Hematology at St. John's Medical College & Hospital Bangalore, Trained in Hemophilia from Royal Free Hospital London, Founder member of Hemophilia Society, Bangalore, Estd. in 1992. He has been associated with hemophilia care for more than two decades.

Dear Friends,

I am glad to present the Vice President-Medical's Report for the year 2010-11. I also would like to acknowledge the cooperation of Dr. Renu Saxena, HOD, Haematology, AIIMS Delhi, EC member, HFI whose presence has strengthened the Medical Board of HFI. Under the able Presidentship of Dr. K Ghosh, we at HFI have been working hard to develop the Treatment facility for Hemophiliacs in India.

The Following important developments have taken place.

Regional Hemophilia Training Center cum Treatment Centres have been designated at Bangalore, Kolkata, New Delhi and Mumbai. Treatment to PWHs as well as Training to Treators, Doctors, Physiotherapists and Laboratory technologists will be carried out. Accommodation for training program will be provided by the center or HFI & travel expense will be supported by the respective chapters.

Increase for AHF support for Special Cell - Increase of AHF support for PWHs for better Treatment has been completed.

AHF support for Emergency - HFI has allocated a good sum for Emergency usage of AHF and the same can be provided to the PWHs on receipt of a prescription from the Local Doctors and report sent to HFI through the Local chapter.

Support for Inhibitors Screening at the National and Local Level: We would encourage all patients who are receiving AHF to have periodic checking of inhibitors atleast after 50 exposure days. This is supported at NIIH, AIIMS and St. Johns Medical College Hospital Bangalore.

Women's issues: There is a budget allocation for Carrier detection and prenatal diagnosis. This is already available at CMCH Vellore, NIIH and AIIMS. Work has begun to develop this at Bangalore also. It is being planned to integrate this in the Thalassaemia program where there is a national program on community control and prenatal diagnosis.

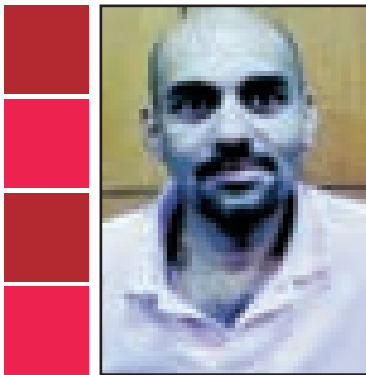
Major Surgeries in Hemophilia: It is heartening to note that surgeries like bilateral hip replacements are done in Tiruchi with Low dose protocols. At Bangalore, Aortic valve replacement, amputation of hip in gangrene in PWH with high titre inhibitor etc have been done.

Clinical trials in Hemophilia in India: There are 5 major clinical trails going on currently.

- ? For Factor VIII deficiency, there is **A Long study** (for Long acting Factor in Hemophilia A). This has the potential to reduce the frequency of giving Factor replacement. The important inclusion is patient should have at least 150 days of exposure which is documented.
- ? For Factor IX deficiency, there is the **B Long study** (for Long acting Factor in Hemophilia B). This also has the potential to reduce the frequency of giving Factor replacement. The important inclusion is that a patient should have at least 100 days of exposure which is documented.
- ? For previously untreated children below 6 yrs of age, there is the SIPPET Study which is looking at development of inhibitor development after giving either recombinant factor or plasma derived factor.
- ? For patients with von Willebrand's disease Type III, there is the **Willate** Study which is looking at the safety and efficacy of this product.
- ? For patients with acute bleeding episodes with inhibitors, there is **ADEPT** study which is looking at the efficacy of a new drug comparable with Novo 7.

There is no charge for these drugs. It is all given free as part of the trial. Arrangements for travel can also be made for patients. Those patients who are interested in participating in these studies can contact me. Other Principal investigators are Dr Sashi Apte (Pune), Dr Alok Srivastava (CMCH Vellore) and Dr Joseph John (CMC Ludhiana)

Dr Cecil Ross



FROM THE VP DEVELOPMENT'S DESK

Mr Vikash Chandraprakash Goel,

A successful business person, associated with HFI for 10 years.

My Dear Friends,

I am humbled to place the Vice President Development's report for the year 2010-11. At the outset, I would like to thank one and all for the support bestowed on me towards the development of Hemophiliacs across India under the umbrella of **Hemophilia Federation (India)**. During the past one year, we at HFI have given utmost priority to the following issues in the development, i.e.

- ? Availability of AHF.
- ? Communication between HFI and Chapters.
- ? National Hemophilia Registry.
- ? Government Lobbying / Public Interest Litigations.
- ? Youth Group

A brief elaboration of the above points:-

Availability of AHF: HFI have been able to procure a huge donation of AHF IX from Kedrion and the same was distributed to the chapters for FREE. World Federation of Hemophilia also distributed FREE AHF VIII to the chapters. There has been a good stock of paid AHF throughout the year.

Communication between HFI and Chapters: With the evolution of internet, the development of HFI's website was initiated with a new address www.hemophilia.in and all chapters were given an e-mail ID to coordinate with each other, HFI staffs, EC members and RCCs in just one click.

National Hemophilia Registry: A National Hemophilia Registry has been developed and thus we can come to an accurate figure on diagnosed PWHs in our Country and the same will help and strengthen our struggle for BETTER TREATMENT to ALL HEMOPHILIACS in INDIA.

Government Lobbying / Public Interest Litigations: HFI has been striving hard in the matter of ADVOCACY or PIL in the various States for FREE AHF and creation of Comprehensive Treatment Centers. We have been successful in various States where FREE AHF is available viz: Assam, Bihar, Delhi, Karnataka, Puducherry, Tamil Nadu, Uttar Pradesh and States like Andhra Pradesh, Rajasthan, Jammu & Kashmir, Sikkim, Orissa and Haryana are on the final stages in procuring AHF.

Youth Group: Youths are the future of this Country and we at HFI are giving highest importance on development of youth groups in various chapters of HFI. To achieve the same we have organized four motivational and capacity building workshops, one National Camp at Rajkot, four Regional Youth camps and few more camps will be organized in the near future.

We have also successfully organized a Job fair and Career counseling for the PWHs where about 9 candidates have got selected for training in various Bangalore based MNCs.

We are also working on a tie-up for vocational training programs for the PWHs in near future.

I take this opportunity to thank our dynamic President Dr. Kanjaksha Ghosh, my fellow EC members and our CEO Mr. S. S. Roychoudhury and HFI staffs for the support and advice given to me, in addition to each and every one of you.

Long Live the Hemophilia Movement. Long Live HFI!

Vikash C. Goel

FROM THE VP FINANCE'S DESK



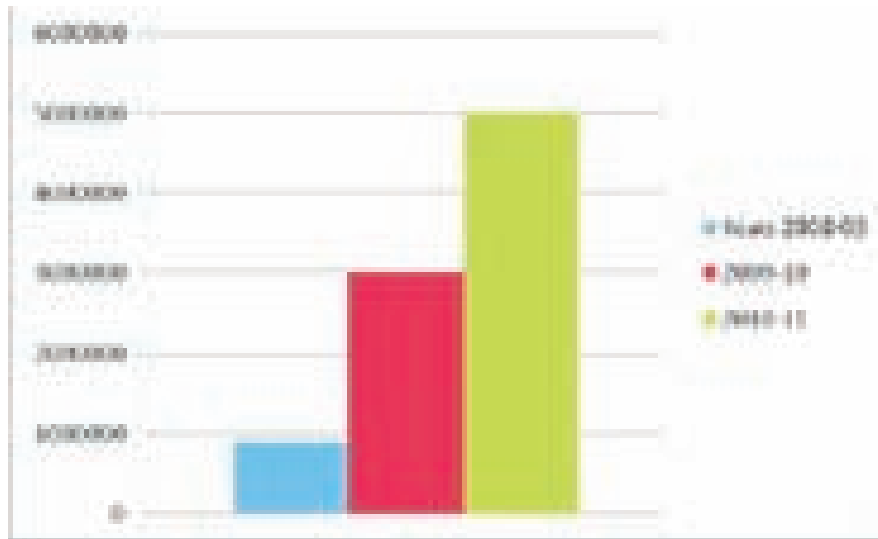
Mr H. M. Sreedhar Rao

Rtd Asst. Director of Co-operative Audit, Govt. of Karnataka, associated with Hemophilia Society Davangere Chapter for 22 years.

Dear Friends,

I am happy to pen down this message for HFI's Annual Report 2010-11. HFI has travelled a long distance in last 28-yrs. It was striding forward right from its inception in 1983 till 2004 when the march forward suddenly stopped because of the untimely death of our founder Mr Ashok B. Verma. After lull period of about five years the organization has again taken a quick stride and during last two years we have seen a highly improved financial growth and good all round achievements.

We have increased our net saving from Rs 9 lacs in 2008-09 to Rs 30 lacs in 2009-10 and Rs 50 lacs in 2010-11. A pie chart given below will give a comprehensive representation of the financial health of Hemophilia Federation (India).

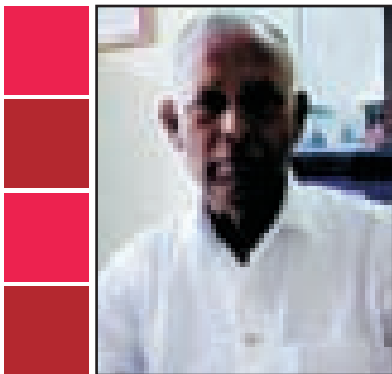


The various corporate connections, advocacy programmes, Fund Raising initiative undertaken by the organization are laudable.

I thank all my colleagues of the Executive Committee and our CEO with all staff for giving me cooperation and comradeship!

H. M. Sreedhar Rao

FROM THE CEO'S DESK



Rtn Wg Cdr (Retd) SS Roychoudhury, FIE

An accomplished multilingual Engineer and a Management degree holder with varied experience for last 45 years with Indian Air Force, NGO's etc. Has a proven record of leading multi-skilled teams to drive projects from pre-development through post-development cycle and capable of mobilizing resources to a phenomenal high level. A high achiever and a well respected person in the development sector. A professional fund raiser who is exposed to both national and international arena of fund raising.

Smooth roads never make good drivers.

A problem free life never makes a person strong.

So never ask life "Why me?" instead challenge it and say "Try me"!

Dear friends and well-wishers of Hemophilia movement,

It's a matter of great pleasure to write for the Annual Report 2011 of Hemophilia Federation (India) for the third year in a row. In close to a thousand days of association with Hemophilia, I've been able to contribute in a small way. Much of this could be only accomplished because of continuous support of the team at Head Office and the extended family spread across the country. Personally, I've grown fond of the fraternity, and take immense pride in my association with each one of you.

Undoubtedly, this journey of three years has been a learning curve. With each day, I've learned something new and unlearned something old. Between tradition and modernity, we've grown as a family and an organization. With this report, I wish to highlight a few achievements over the year gone by, and the major challenges that await us.

Communication: Over the last two years, setting up of the Communication Department has indeed helped us streamline the flow of information across the organization. *Hemophilia News*, our quarterly newsletter started in 2009, has been a regular feature. We have published annual reports regularly over the years and shared with our partners Corporates, Donors and Sponsors, Funding Agencies, and Governmental and Non-Governmental organizations.

In a very important move, we have launched our new website (www.hemophilia.in), a dynamic web interface which is a rich resource on Hemophilia. The National Hemophilia Registry (NHR) website (www.hemophiliaregistry.in) too has been launched, and we now have a centralized resource for all registered Hemophiliacs in the country. We have published literature on Managing Hemophilia, and many other documents like posters, guide-books and so on, that have helped us spread public awareness on Hemophilia.

We would emerge even stronger communicators if we are continuously updated on various activities and developments from all the Chapters at least once in a fortnight. With this report, I would also reiterate my request of sharing information in terms of quarterly and annual reports from your respective Chapters.

Resource Mobilization: We have come across as a credible organization over the last year. 35AC has come to us, making us one of the few chosen non-profits selected by the Government of India to allow a 100% tax-exemption to all donations made to us. This is indeed a great achievement. Charged up with this accomplishment, we have reinforced our fundraising campaign. All these efforts have given us positive returns.

Lobbying and Advocacy: We have been lobbying at a large scale with influential organizations and individuals to take further the cause of Hemophilia, which gets sidelined more often than not because of its niche nature. We

are having dialogue with National AIDS Control Organization (NACO) for inclusion of Hemophilia in Central Government National Health Scheme. We have also spoken to various MLAs and MPs for approaching Ministers of Health in the State and Central Governments.

Programmes: Hemophilia programmes have gained a substantial momentum in the recent past. Important organizations have come forward to support our cause. Oil and Natural Gas Corporation (ONGC) extended its support to 1000 CwH this year. Steel Authority of India Limited (SAIL), too sponsored AHF for 100 PwH. Volkart Foundation empowered Hemophilia Chapters this year as well. Hans Foundation grants would support treatment and Education of 25 and 50 CwH respectively. Under the Save a Child (SAC) scheme, Hemophilia Society of UK came forward to support AHF for 85 CwH. Save One Life (SOL), sponsored by LA Kelley Communications, USA, too, supported 319 CwH across India. Individual and Corporate support through GiveIndia, Yellow Umbrella and other charities has been encouraging too.

Going beyond, these are encouraging developments. We have come a long way since we embarked upon making Hemophilia a movement in India. We have been successful in making that first stir, and I'm sure together, we are going to grow bigger and stronger in days to come.

Blessings and best wishes!



Rtn Wg Cdr (Retd) SS Roychoudhury, FIE

NATIONAL INITIATIVES

PROGRAMME HIGHLIGHTS 2010-11

- HEAT -ONGC
- VOLKART
- SAVE ONE LIFE
- SAVE A CHILD
- SAIL
- GIVE INDIA
- THE HANS FOUNDATION
- NHYFI



RESOURCE MOBILIZATION

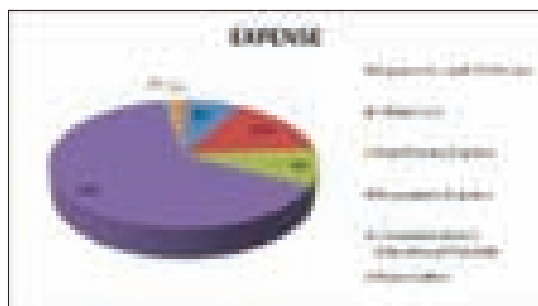
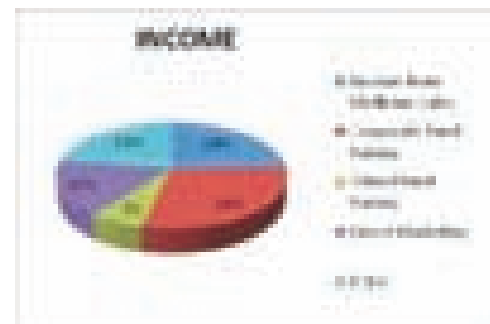
The year 2010-11 saw a distinct growth of Hemophilia Federation in the arena of Resource Mobilization. Some of the initiatives taken in the year 2009-10 started yielding results in the year 2010-11. All these things were made possible because of the committed effort on the part of a very small team of resource mobilizers of HFI.

The net surplus after all expenses has gradually increased from a figure of 9 lacs in 2008-09 to 27 lacs in 2009-10 to 51 lacs in 2010-11. This itself speaks of financial health of the organization. But we are nowhere near our cherished target which we plan to achieve in the coming years by focusing more on increasing the corporate connections and expanding the ambit of Direct Marketing. We have recruited a new Resource Executive for Southern Region & we plan to do for Western Region as well. Graphical representation given below will show the growth of Resource Mobilization in HFI over last five years.



FINANCIAL STATEMENT

Income from Medicine Sales	4884486
Corporate Fund Raising	5900000
School Fund Raising	1367986
Direct Marketing	3373256
FCRA	4544095



Expense towards PWH Care	1515736
Admin Cost	2970936
Fund Raising Expense	1790937.5
Programme Expense	12215998
Communication & Educational Materials	128570
Depreciation	410677.4

Friends & Supporter of Hemophiliacs

Corporates

1. Oil and Natural Gas Corporation Ltd. (ONGC)
2. Steel Authority of India (SAIL)
3. The Hans Foundation

Schools: We have been able in tapping more schools like Bhiwani, Hissar, Ganganagar Saharanpur, Mujaffarnagar, Rajpura, Sangrur and Srinagar in North, and Siliguri, Asansol, Raniganj, Chittaranjan, Ranchi, Kharagpur, Tinsukia, Silchar in East and Goa and Ahmedabad in the West.

Donation Box: Installation of the number of Donation Boxes in Delhi has been increased by 125%.

Donor Database also increased substantially over last two years.

PROGRAMME HIGHLIGHTS



“HEAT” PROJECT

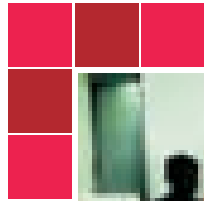
Hemophilia Federation (India) successfully executed ONGC sponsored Project “HEAT” (Hemophiliacs Education and Transformation) by giving educational support to 1000 children across the country from BPL and very poor families. However, during 2nd phase of the project implementation 15 CWH students dropped out and 1 CWH died, as a result we have surrendered the sponsorship amount of these children to ONGC as per the MOU. This project has definitely brought some awakening amongst the hemophiliac children of the country because this is the first time that an Indian Corporate has supported such a challenging project. ■

VOLKART PROJECT

With the support of Volkart Foundation for a period spanning over two years i.e. 2009-10 and 2010-11, Hemophilia Federation (India) successfully completed the project “Extending Hemophilia Care to person with Hemophilia through Chapter Empowerment”.

The programme was implemented in four chapters (Bikaner, Surat, Bhadrak and Karaikal) who were active at the community level but were unable to reach out to the larger group owing lack of technical support and financial constraints. ■





SAVE ONE LIFE

“**Save One Life-USA**” has been supporting poor children with Hemophilia with general donations of 20 US dollars per month through individual foreign donors. This support has been very helpful in fulfilling the basic necessities of these poor children like sufficient meals or school fees, books etc. The number of children supported under this project has increased considerably over the years. At present 345 CWH are sponsored under **Save One Life**. We are very thankful to Laurie Kelley, founder and President of Save One Life and LA Kelley Communications, all the donors and hope that the numbers of beneficiary under this project keep increasing at the same pace and even more rapidly. ■



*“When **Save One Life** was conceived by Laureen A. Kelley in the year 2001, India was the first country to get adopted. I was involved with Save One Life since its inception in the capacity of Vice President-Development (VPD) of HFI. After my tenure as VPD from HFI in 2009 Laurie requested me to be the coordinator of the program for India which I readily accepted. This has given me a great opportunity to directly interact with the PWHs across the country. Save One Life has become dear to my heart which is supporting more than 350 beneficiaries through 21 Program partners (Chapters)”.*

- Mrs Usha Parthasarathy, Save One Life Coordinator (India).



SAVE A CHILD

Through “**Sponsor AC hild-UK**”, individual donors have been providing treatment (AHF) support of 20 pounds per month to 76 poor children suffering with hemophilia. Through this timely support many children could be prevented from getting disabled or dying. We are very thankful to all our donors for their concern for distressed children in India & anticipate their continued support. ■

SAIL PROJECT

In our country approximately 90% of the P/CwH (Persons/Children with Hemophilia) are either from very poor families or from families Below Poverty Line (BPL). Therefore most of them are not able to get timely, sufficient & appropriate treatment due to high cost of Anti Hemophilia Factor (AHF), which forced them to depend on infusion of unsafe, wet blood products such as Fresh Frozen Plasma (FFP) or lyophilized cryoprecipitate. These necessarily expose patients to blood borne infections such as HIV/AIDS and Hepatitis Infections. If a person or child with hemophilia contracts any of these infections in addition to his inherited disorder, then the resulting complications can be extremely harmful physically, emotionally and financially.

In order to make available free factor support to these HIV/AIDS affected beneficiaries under Special Cell, Steel Authority of India Limited (SAIL) provided 1000 IUs of Anti Hemophiliacs Factors (AHF) at the rate of Rs. 10/- per unit for 100 beneficiaries worth Rs. 10 lacs.

As all of these 100 beneficiaries are hemophiliacs and are HIV+ patients, the names of these patients can not be disclosed due to reasons of confidentiality while implementation of the project. ■

GIVEINDIA

Hemophilia Federation (India) has been associated with GiveIndia for two years. In the year 2010 after going through a very stringent process of registration HFI has got registered for provisional listing on the Give Online Donation Channel at www.giveindia.org. Now through this channel donors from all over country abet the PWH/ CWH through several sponsorship like sponsorship for AHF, Education, Carrier Detection Test and Pre Natal Diagnosis etc. During this one year HFI has acquired more than 2 Lakh as donation through this channel. By using these donations Hemophilia Federation (India) is able to provide life saving AHF to 5 PWHs in emergency and educational support for one year to 12 CwH who are in verge of discontinuing their study due to financial crisis. HFI has also sponsored 3 Carrier Detection Tests and 2 Prenatal Diagnosis in its different chapters. Apart from this Hemophilia Federation (India) also participates in several events organized by Give India time to time like, IndiaGiving Challenge, Tax Giving Challenge and it has also created a I Give Page in the portal of Give India to acquire donations from all over the world to continue to support the hemophiliacs of the country . ■

Preventing Hemophilia and ensuring better life though Carrier Detection Test



Sreeji



Vaibhavi Patel

"Hemophilia Federation (India) underwent GiveIndia's due diligence process and was listed on our website www.giveindia.org in June-2010. During FY2010-11, they received Rs.214251.00 from our donors towards their programmes. Their feedback reports to our donors are well written with details of the beneficiary and impact of benefit coming through clearly. We wish them every success".

*Gopi Venkataraman
GiveIndia Listing Team*

THE HANS FOUNDATION

For last two years **The Hans Foundation** has been supporting the cause of hemophilia through projects for treatment, education and nationwide awareness programs on Hemophilia. With their support we have been able to provide educational support to 50 children with hemophilia. With this support deserving children who wanted to pursue their education but were not being able to do so because of financial constraints were able to continue their studies in a more dignified way and can now dream of a better and secured future.

Through treatment (AHF) support, 25 P/CWH from poor and BPL families' were able to attend school more regularly & also participate in other extra curricular activities. Their discipline and social habits have improved & above all they could be prevented from getting disabled or dying because of this timely support. Adults were able to work in a better way and were eased from the mental stress of being a burden on the family.



Through project CHETANA awareness on Hemophilia has been spread across the country through schools, colleges and educational institutions. This has been a very effective programme as far as outreach, visibility, registration of patients, and prevention of Hemophilia through awareness & alongside fund raising is concerned.



For our march towards alleviation of sufferings of the Hemophiliacs of India, we have found these very highly capable and credible partners. Together we will carry on our crusade against the suffering brethren our great country.

In the past year "The Hans Foundation" partnered Hemophilia Federation (India) to support children suffering with hemophilia, through an integrated programme of treatment, educational support as well as awareness programmes. It gives me great satisfaction that educational support was extended to 50 school children and treatment support to 25 children from poor and BPL families. The CHETNA project was also instrumental in spreading awareness across the country in schools, colleges & other educational institutions. I wish the Hemophilia Federation (India) the very best in their endeavour in mitigating of sufferings of Hemophiliacs across India.

Sweta Rawat, Managing Director, The Hans Foundation



NATIONAL HEMOPHILIA YOUTH FEDERATION

The year 2010-11 was a great year for the youth of HFI filled with continuous youth oriented activities. Year 2010 ended with a high note with "Bye Bye 2010" at the Rajkot Chapter's National Youth Camp where 46 participants from across India participated and benefitted. A North regional camp was organized by the Goa Chapter in Punjab. This year also HFI witnessed election of its first reserved youth EC member.

HFI with support of Danish Haemophilia Society & Disabled Peoples Organization Denmark initiated the project "Young Voices on Hemophilia in India" which saw remarkable success in the past year and was instrumental in the development of young PWHs across India. The core objective of the project is to build a Youth group in all the chapters of HFI with a strong vision to support the cause of Hemophilia under the banner of HFI. A team of 4 regional heads and 4 assistant regional heads are formed along with the coordinator of the project.

With the above objective in mind a national leadership workshop was organized in Mumbai and the main agenda was to individually develop young PWHs to be leaders of tomorrow. Prominent trainers were invited to speak on leadership, project management etc. Ten participants from each region attended the training programme. Subsequently, after 3 months 4 Motivational one-day Camps in Bangalore, Kolkata, Mumbai and Varanasi were organized to refresh and motivate the participants on the Mumbai Leadership Training program follow up. The youth project was scheduled to be over by 31st March 2011 but DHS and DPOD were kind enough to extend the project until 31st Dec. 2011.

Mr Terkel Andersen (President Danish Haemophilia Society) and Ms. Naja Skouw-Rasmussen (steering committee member of the project) visited HFI offices for a special Steering committee meeting on 28th and 29th March 2011. They met our CEO and the 4 Regional Heads and Co-ordinator, to discuss the future Activity of the project.

Four Regional Camps were organized during the months of June-July 2011; From 18th-20th June camp was held at Varanasi (North), 8-10th July at Bangalore (South), 22nd-24th July at Mumbai (West) and 23rd- 26th July at Aritar, Sikkim (East) with around 30 participants in attendance in each of the camp. These camps aimed at providing a platform for the youth where they could exchange their ideas, express and share their experiences, improve their personality and learn leadership skills with their fellow PWHs of the region. Activities included motivational talks by EC members and guest speakers of the respective region, group interactive





work for disability and organized the event for most disabilities. This Job fair was a stepping stone in our endeavor to empower as many PWHs as possible by providing placements in suitable positions. On a trial basis it was held only for the PWHs in Karnataka. This event saw around 40 PWHs from Karnataka participating; 15 PWHs & 1 Hemophilia Carrier were placed successfully. We are sure that Job Fairs of similar kind will encourage PWHs to take education and career planning with greater enthusiasm and zeal.

sessions, fun and frolic, etc. Physiotherapy sessions, Self-infusion and Career counseling were some of the highlights.

Some of the main attractions were:

South Zone: A motivational talk was given by Mr. Ashish Ballal (former Indian National Hockey team Goal Keeper) on how to fight against and face any hostile situation by being positive, focused and dedicated to the goals that would lead to success in life. A tribute to all our patrons was paid by participants walking down the ramp in a PWH man hunt/fashion show with props and the logos of our sponsors.

North Zone: Yoga sessions and lectures from faculties of Banaras Hindi University.

West Zone: DJ Night and Rain Dance.

East Zone: Sight Seeing near China Border, Lampokhuri Lake, Zuluk, Nathula Pass.

Pondicherry & Coimbatore chapters had twining camps for their youth, which strengthen the chapters of the region. Surat chapter youth group organized blood donation camps regularly throughout the year. Angamally chapter organized a state level youth camp in Kerala.

Our Vision is to enable the youth to take up more responsibilities and our young hemophiliacs to be future leaders in their respective fields and also serve Hemophilia Federation (India) in days to come for the development of PWH in India.

Reported by Premroop Alva (Youth Representative to EC) & Mukesh Garodia (National Youth Coordinator)

Job Fair

Presentation on Hemophilia and the need for job openings for young PWHs were made to the Human Resource heads of various companies. The Young Voices of Hemophilia tied up with other like-minded NGOs who



Giving New Life Through Heart Valve Replacement



Twenty three year old Praveen, a PWH from a remote village of Hassan district of Karnataka was diagnosed with Aortic Valve Regurgitation (AVR). Praveen's family was in panic and did not have sufficient money even to travel to the hospital. To incur the expenditure of an open heart surgery for a poor Hemophiliac was out of reach for them. Cost of the Valve alone comes to around Rs.60,000/, apart from treatment, Hospital charges, Factors and cost of management of post ops etc. On behalf of HFI Mr. Premroop Alva (EC member) and Mr. Vikash Goel (Vice President Development) took initiative in organizing surgery for Praveen. They approached several donors and Mr. Prem prepared detail case report of Praveen and approached Narayana Hirudayalaya hospital at Bangalore. Narayana Hirudayalaya Hospital came forward to do free surgery but arrangement of factor support was the biggest challenge.

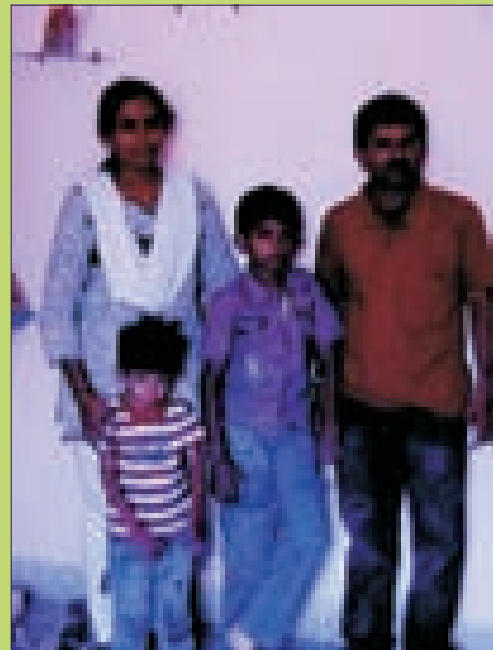
Thanks to Save-One-Life project team Ms Lauren Kelly and Mrs. Usha Parthasarathy, who covered the surgery with free factor support. Surgery was successful under the supervision of Dr. Cecil Ross. Praveen is doing very well now.

This surgery was counted as one of the rare procedures on PWH and created history from our Indian medical team. Thanks to Narayana Hirudayalaya team and Dr. Cecil Ross which was a milestone. We are grateful to Ms Lauren Kelly and Mrs. Usha Parthasarathy for the medicine support for saving Praveen's life and allow him to live thereafter.

About 4-5 similar major surgeries were carried out in different hospitals across the country and all are successful. ■

Lending A Helping Hand

Mrs Deepa Chavda is a Career from Rajkot, Gujarat. Her first child Rishiraj Chavda (Age-12) was born with hemophilia VIII deficiency (sever). With no family history of hemophilia Deepa was worried about conceiving of her second child. Before giving birth to the child she wanted to know whether the child has hemophilia. Therefore, she sought help and guidance from Hemophilia Society Rajkot chapter affiliated to HFI. Mr Kiranbhai Avasia (President of the Society) suggested her to go for Pre-natal diagnosis. Due to low family income her family was unable to meet the diagnosis cost.



HFI's Intervention and Impact

HFI reviewed the case & arranged donations for her diagnosis. Mrs Sonal Sakaria, member of the society accompanied Mrs Deepa to KEM Hospital, Mumbai for the test. Her traveling, lodging and diagnosis costs were sponsored by HFI. The result was negative.

She was thankful to God that her child was not a hemophilic. She was aware of the severity and difficulties of brining up of a child with hemophilia due to its expensive treatment & management. Due to awareness, knowledge and proper guidance Deepa was able to give birth her second child without any apprehension. Now Deepa voluntarily works for the cause of hemophiliacs in association with the Rajkot chapter. ■

REGIONAL INITIATIVES



Healingt heH emophilä cs



NORTHERN REGION



- ☞ Hemophilia Society Yamuna Nagar has been newly registered and affiliated to HFI. RC meetings and various camps were held regularly.
- ☞ Bareilly chapter organized CME and a workshop in association with Indian Medical Association (IMA) at Bareilly on 31st Oct. 2011. More than 50 doctors, medical students and PWHs participated benefitted from it.
- ☞ Filing of PIL process is on in the states of U.P., Uttrakhand, Haryana and Chandigarh under the leadership of Mr Vinay Manchanda.
- ☞ The Govt. of Uttar Pradesh has discontinued giving grant to Banaras Hindu University (BHU) and Aligarh Muslim

University (AMU) saying that this two designated centers are governed by the Central Govt. and hence cannot be controlled by the DG Health and DG Education of U.P. Similarly, action has been taken by the Central Govt. in respect of JNU also. Being Central institutions they themselves arrange the grants to treat Hemophilia patients at their centers. On this, the court has directed the union of India to explain as to why a direction is not issued to them for providing necessary funds to the aforesaid Universities for the purposes of necessary Factors for the treatment of Hemophilia Patients.

SOUTHERN REGION

Looking back the year 2010, the reporting period unfolded with the meet the Southern Regional Council at Tirunelveli. Various decisions and resolutions had been adopted. One among the many had been the first time introduction of the monthly & yearly review formats for the Chapters.

The govt. of Tamil Nadu had drafted a Bill for free distribution of Factors in all Government Medical College Hospitals of the State. Dr Anburajan's personal visit to Kerala and his interactive sessions with the PWH of Angamaly, Calicut and Kunnampulam Chapters were encouraging for the PWHs. During South RC Meeting held in March at Trissur (Kerala) members were given best Pillar Awards and Letters of Appreciation for their noble services to the PWHs. Hypnotherapy was demonstrated by Dr C. Reghunandhan during this Meet.

Kannanur (Kerala) and Hubli-Dharwad (Karnataka) were newly registered as a society and affiliated to HFI this year & joined the hemophilia family of the South Region.

Two packages of Free Factor IX had been distributed all across the region. The World Hemophilia Day was commemorated with much pomp and fanfare in all the chapters to create awareness among the public and the local administrations. *Kovai- Pudukkottai Sangamam*, Youth Camp was organized by the Youth of Coimbatore and Pondicherry Chapters.

Kerala state level youth camp was held at Trissur. The Civic Leader and Team Work Awards were presented to members of Trichy chapter for their dedication towards the cause of the PWHs. A paper on Water Therapy was presented by Dr. Allwyn Christuraj, a PWH during the Bangalore RCM.

A Youth Camp was organized in the Garden City of Bangalore to reinforce leadership skills among the young PWH of the region.

South Region is happy to host the AGM 2011 at **Cape Comorin**, at Kanyakumari, the very confluence of the three water-bodies the Arabian Sea, the Bay of Bengal and the Indian Ocean.

Reported by Dr Anburajan, RCC-South



EASTERN REGION

During this year significant achievements has been observed but much more need to be done in the Eastern Region. Our main objective is to improve the quality of life of all PWHs and identify more and more undiagnosed PWHs from all the chapters of eastern region.

We thank all the schools and colleges for their support and sponsorships towards various programmes. We also appreciate their concern and commitment towards the cause. Total Rs. 501,203/- were raised during the period of April 2010- March 2011 through SFR programme by Mr Arun Pandit, R.E(East). Calcutta chapter was kind enough to extend their support to the PWHs from

Durgapur, Siliguri, Khragpur and Jamshedpur during their medical treatment at Kolkata. Due to timely factor support of HFI at the time of emergency, **lives of Mr Susanta Paul and Mr Prasun Bhandi were saved** who were suffering with severe ilipsoas and CNS bleeding. Durgapur chapter is grateful to HFI for giving new life and brining hope to them.

Mrs. Laureen A. Kelley, founder of SOL programme and Mrs. Usha Parthasarathy, Co-ordinator, SOL programme in India visited Kolkata, Durgapur and Bhubeneswar Chapter in the month of October 2010 and met all the SOL beneficiaries and their families. Mrs. Laurie appreciated Durgapur chapter for proper maintenance of the record and discipline of the chapter. We thank Kelly Foundation, USA for giving 7, 2010 IUS of factor VIII and Dr. Sharad Jahagirdar, Mumbai for donating Rs.25000/- for the treatment support of Biru Kumar Singh a PWH of Tinsukia Chapter, Assam who went through major operation in KEM Mumbai recently.

Bhadrak chapter started a Care Centre for the hemophilia patient at Balasore at the Chamber of Dr. A. Behera. Bhadrak Chapter. A youth meet was organized on 18 Jan. 2011 at Balasore. Women's Group of Durgapur Chapter successfully organized parents camp on 21st Jan. 2011 at Mukutmonipur, Bankura. Guwahati Chapter had a remarkable achievement. Now FREE AHF is available in Guwahati Medical College & Hospital (GMCH) and they are trying to develop a Hemophilia Treatment Centre in GMCH. Jamshedpur Chapter organized a blood donation camp at Jamshedpur Blood Bank on 17 April, 2011. On this occasion Mrs. Alpana Bhattacharjee, Secretary of ANWESHA a local NGO announced to give educational support to two CWH @ 3000/- annually.

Amity Kolkata Half Marathon was held on 12 March, HFI members and Kolkata Chapter participated in the event to raise donation and create awareness about hemophilia. Awareness Program about the hemophilia and its associated problems organized by Kolkata Chapter on 16 February 2011, at IHTM (Medical College Hospital), with the support of Baxter India.

A Critical Prostate operation of a PWH was successfully done at Patna Medical College, Bihar with all factor support at free of cost. For the first time Kharagpur and Tinsukia Chapter conducted their 1 AGM with a medical and Physiotherapy camp for the PWHs ever since its foundation. The Youth are the strength and asset of a nation and HFI also. Youth group of eastern region organized a Youth Camp at Sikim, West bengal from 23rd to 26th July 2011. A PIL has been filed in the West Bengal High Court against the state government for failing to provide adequate infrastructure and AHF for the treatment of hemophilia patients and very shortly the state Govt. will give their decision. Three Regional Council meetings were held at Patna, Siliguri and Kolkata during the year.

We lost our highly respectable leader Mr. Piyush Kanti Saha, Secretary and Founder of Agartala chapter, Tripura. We pray to God that his soul rests in peace.

Reported by Mr Ajoy Kumar Roy, RCC-East



WESTERN REGION

Rajkot Chapter: One of the strongest Chapters in western region with the committed support of Kiran Bhai Avasia. Chapter has its own Building with Diagnosis treatment facility conducting Physiotherapy camp on daily basis & Homeopathy camp on monthly basis. Organized the National Youth Camp successfully. Career Detection Test camp was organized and 150 blood samples have been sent to NIIH, KEM Mumbai for test.

Indore Chapter: Old chapter has been reactivated with new name 'Hemophilia Society Indore City'. New EC was formed in the presence of Mr. Santosh Lalwani as the President & Mr. Mahendra Vikkar as the Secretary. They have formed a Youth Group which is actively involved in creating new & active Chapter. Dr. Hariyali is a very good supporter in medical side at MYH Hospital. He is also trying to start comprehensive care unit in MYH Hospital. He is also lobbying with MP Government for free treatment of Hemophilics. Indore Chapter has organized RCC Meeting also.

Goa Chapter: New chapter was formed at Goa with the support of Mrs. Manjeet Chohan. Within a short period they have already organized CME in Goa Medical College & also organized camp. During her visit to UK Mrs Manjeet and her team have organized a small fund raising event and raised 1200 pounds for future Chapter activity.

Kolhapur Chapter: After a long gap, Kolhapur chapter is now actively working for chapter development with the support of Dr. Manjarekar (President of Kolhapur Chapter & Ex-civil surgeon of the District). He is also trying to start Comprehensive Care Unit in Pramilaraje Hospital, Kolhapur. He has organized CME & RCC meeting in Kolhapur.

Dhule Chapter: New Executive committees were selected, Mr. Devram Bhai Harsod as the President & Mr. Harshal Kale, as the Secretary. The local youths are actively working for chapter. Dhule Chapter has organized Homeopathy camp with the help of local Rotaract Club.

Nashik Chapter: Regular Homeopathy Camps are being organized with the help of Dr. Tapaskumar Kundu with good result.

Jabalpur Chapter: Chapter is working very well under Mrs. Kiran Gangarade.

Nagpur Chapter: Chapter is working very well under Mrs. Anuradha Sambre.

Vadodara Chapter: Chapter is working very well under Mr. Dineshbhai Vadhada.

Surat Chapter: Chapter is working very well under Mr. Mukesh Bhai and his youth team. They have also organized Blood camp every month.

Mumbai Chapter: Mumbai is one of the very good active chapters in western region. Chapter has arranged various programmes like Eduinfotainment Trip to Nehru Science Centre on World Environment Day for Plantation, participated in Standard Chattered Mumbai Half Marathon, Homeopathy camp, Dental Camp etc. In this Homeopathy camp 42 Hemophilics were present and Dr. Kundu from Nashik with his team had distributed free Homeopathy medicine to those patients. Mumbai Chapter is also lobbying with Maharashtra Government for free treatment of Hemophilics.



Reported by Dr Devila Sahoo, RCC West

Highlights on Other Activities

COMMUNICATION

Communication is necessary for every interaction. Communication is necessary for working together. Working together can provide us with a wider audience, more political strength and more knowledge. Therefore we need communication, and we need to improve it all the time.

Over the year both external and Internal communication system of HFI has been strengthened by means of introducing official email IDs, launching of new interactive website, regular publication of quarterly newsletter, souvenir, awareness posters and brochures, Fund Raising forms, emails blasts, Occasional Mailers etc.

During the year 2010-11

- 10 thousand posters for awareness and visibility were printed and distributed.
- More than 15,000 copies of Newsletters were printed and distributed to all the chapters, Corporates, Donors and Sponsors, Funding Agencies, Governmental and Non-Governmental organizations etc.
- Launching of the New Website: www.hemophilia.in
- Launching of NHR Website: www.hemophiliaregistry.in
- 1000 copies of Practical Guide for Persons with Hemophilia and Guidelines for Hemophilia and Guidelines sent in India were printed and distributed in all part of India for the purpose of education and awareness on Hemophilia for both the medical fraternity and the public

LOBBYING AND ADVOCACY

Advocacy/PIL/Govt. Involvement: Eventual goal of HFI and its chapters is to involve Govt. of the day through its innumerable hospitals across the country in the modern care of PWH, which is through development of comprehensive care facility along with provision of free factor concentrates and products. This is being attempted at several levels;

- By discussing and presenting the plight of PWH to the Health Ministers and various high officials at centre and state level.
- Involving individual MPs and MLAs of different political parties to raise pertinent questions regarding delivery of hemophilia care for PWH in various hospitals of the country.
- Helping develop general opinion amongst various medical and quasi medical bodies on the need for Govt. to provide such care.
- Publishing research articles and other data which permanently record still unmet needs of PWH in this country. Making Govt. act on court orders through Public Interest Litigation (PIL).
- HFI has already formed a PIL cell to guide the chapters to register PIL in respective High Courts. This year Rajasthan state joins as successful PIL litigant. This credit goes to Mr. Mukesh Gupta of Jaipur Chapter and his team.
- Lobbying with NACO for inclusion of Hemophilia in Central Government National Health Scheme is on progress.

These kind of activities helped Govt. of Assam, Gujarat and Kerala opening their doors for care of PWH, though this door is only partially open. Hence on behalf of HFI I congratulate all these state chapter key persons who successfully lobbied for the cause. Kiranbhai Avasia, Mukesh Garodia, Mr. Raghunandan are some of the personalities who along with their team are fighting for the cause. These names are indicative and is not comprehensive, as behind each of the names there are others who are fighting for the

cause. States of Andhra Pradesh, Tamil Nadu have already agreed to get involved in comprehensive haemophilia care. This happened because of successful lobbying by various people but especially by Dr. Alok Srivastava from CMC, Vellore. Recently our Vice President (Development), Mr. Vikash Goel was able to arrange a meeting between the Health Minister of Orissa, EC members of Orissa Chapter and Dr. Dipika Mohanty. I am given to understand that the results were fruitful and the Hon'ble Minister has promised to provide all the help to PWH of the state. So it can be seen that over last few years (i) Karnataka (ii) Pondicherry (iii) Tamil Nadu (iv) Andhra Pradesh (v) Delhi (vi) Assam (vii) UP (viii) Rajasthan (ix) Bihar (x) Gujarat (xi) Kerala (xii) Goa has made either partial or full progress in engaging Govt of the states for providing help to PWH. We are sure within short period of time other states will also follow suit.

Dr. Ghosh and his team are engaged with the Govt. of Maharashtra in this direction. A blue print for haemophilia management for the whole country to the Central Govt has been already submitted to the govt. We are hopeful that in the 12th Five Year Plan we will see a larger budget allocation for haemophilia care.

Dr. Ghosh and his team also has engaged Indian Council of Medical Research (ICMR) and received some fund allocation for training doctors and technicians for the diagnosis of coagulation disorders. First workshop involving 20 candidates from states of Tripura, Manipur, Mizoram, Madhya Pradesh, Chattishgarh and Orissa have already taken place. Dr Shrimati Shetty is playing a very important role in this training programme. Above account clearly shows that HFI and its contingent chapters are actively engaging government towards fruitful implementation of diagnosis and care for PWH in the country.

Spreading the expertise of management of PWH across the country:

One of the long felt desire of the organization is to bring the quality haemophilia care at patient's doorsteps. To this end, HFI has trained many doctors, technicians, physiotherapists. Slowly this effort is paying off. In addition, many doctors are now becoming trained haematologists in our country and many multinational companies are selling their machines and reagents which are being regularly used for coagulation tests. All this together has produced a conducive environment which will help HFI to bring haemophilia care at door steps. Dr. Maganti Prasad at Vijaywada chapter has already saved many PWH through neurosurgery, gastro intestinal and orthopaedic surgery. Pune chapter is getting their all the surgeries in PWH done locally.



Nashik chapter has successfully operated on a PWH with fracture neck of femur, Kolkata has accomplished a gall bladder surgery on a PWH with only 15,000 i.u. of factor VIII. St. John's Medical College, Bangalore is regularly doing difficult procedures on severe haemophilia patients. There are likely to be many more examples which probably have missed out. However, all these examples show our growing ability to manage difficult challenges for PWH.

Carrier Detection & Prenatal Diagnosis: CD and PND are now regularly being done at Lucknow, Chandigarh, AIIMS, Delhi, Sir Gangaram Hospital, Delhi, CMC, Vellore and NIIH at KEM Hospital Mumbai. CCMB, Hyderabad is capable of giving regular service to Hyderabad but for some unknown reason they have stopped such service. Similarly Rajiv Gandhi Institute of Biotechnology at Trivandrum has all the molecular biology techniques available to help diagnose our carrier patients and also help in antenatal cases. Interest of local chapters are extremely important to engage these institutes to help them. Presently, more than 100 families each year take the help of prenatal diagnosis and carrier detection at these centres.

In the beginning of such services and even during the heyday of DANIDA project implementation only 4-5 prenatal

diagnosis/year was envisaged. There are at least other 5 or 6 centres across the country which will be ready with this facility any time in future. This year, a team from NIIH visited Rajkot Chapter where a clinic for carrier detection and prenatal diagnosis was established and around 35 families of PWH have taken advantage of this camp.



CONTINUING MEDICAL EDUCATION (CMEs):

12 CME programmes across the country have been conducted. These programmes were substantially assisted by pharmaceutical companies and these CMEs were spread across the country. We are encouraging various medical societies to hold CME's on bleeding disorders, their management, prevention etc. CMEs have substantial implications in improving the skills and knowledge of doctors and other allied specialists in improving Hemophilia care in the country.

CAMPS: Quite a number of regional camps were conducted this year. National camp was also conducted at Kolhapur. These camps bring PWH from different parts of the country together in a brotherly bonhomie. In addition to learning certain skills, these camps generate cultural exchange and lots of learning by association. It also teaches a PWH how to live independently without the protection of parents.

YOUTH GROUPS: One of the important facets of activity of HFI is the activity of youth groups. Young PWH are our future hence HFI is making every attempt to invest in our future. Already in HFI and in majority of the chapters there is atleast one E.C. member from youth group. Danish hemophilia society has provided some financial help to strengthen these youth activities. This year from each region of HFI youth groups had their meetings, they have chalked out their future activities geared towards the development of PWH youth in India.

WOMEN GROUP: HFI regularly supports women group meets and many chapters conduct women meet regularly. These meetings are very important towards understanding the challenges faced by mother, sister, wife of a PWH and relevant programmes toward mitigating such challenges can be taken. Carrier detection and Prenatal diagnosis are two direct intervention programmes to reduce anxieties of these groups. HFI this year has decided to fund a given number of Prenatal diagnosis activities across the country.

"I cordially thank all the staffs of Hemophilia Federation (India) for sending 271 unit of Factor VIII to stop bleeding of my son, Abhisekk Kumar. I am really grateful to HFI for this support during emergency as now a days we even cannot expect this kind of support from our own family members. Earlier we had to go to PGI Chandigarh, where Plasma was provided to the patient and for this treatment patients were forced to be admitted there for couple of days. But now this continuous support from HFI has enabled my son to attend school regularly and enhance his brilliance. Due to this bright nature his friend and teachers also support him whole heartedly."

- Surendra Mohan, Ludhiana

SPECIAL CELL REPORT 2010-11

As per the mandate of the Management and Executive of HFI, the Special Needs Cell has been functioning well and providing support to around 200 registered PWH all over India.

Total amount reimbursed to the beneficiaries	Rs 85846/-	
Factor VIII (A)	80195 IUS	8800 IUS
Factor IX (B)	8800 IUS	Rs 105600/-

NATIONAL HEMOPHILIA REGISTRY (NHR)

We have started **National Hemophilia Registry (NHR)** of all the PWH/CWH in India. ([Http://hemophiliaregistry.in](http://hemophiliaregistry.in)) NHR consists of Personal, medical, economical status of every PWH. Dedicated team for co-ordination and data processing team is set in Bangalore to help all the chapters in data collections. We have completed Phase-1 which is application development and deployment in secured environment. 90% of our PWH data is in place. Our NHR provides vital information for Medicine Distribution, Government Lobbying, Program Initiation to assist PWH in better lifestyle.

FINANCIAL STATEMENT

D. K. A. ASSOCIATES **CHARTERED ACCOUNTANTS**

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FORM NO. 11B

[See Rule 17 B]

AUDIT REPORT UNDER SECTION 11A(3) OF THE INCOME TAX ACT, 1961, IN THE CASE OF CHARITABLE OR RELIGIOUS TRUSTS OR INSTITUTIONS

We have examined the Balance Sheet of Hemophilia Federation (India), A-128, Mohanmadyar (Behind Bhaiji Cama Place), New Delhi - 110 066 as at 31st March, 2011 and the Income & Expenditure Account for the year ended on that date which are in agreement with the books of account maintained by the said Society. These financial statements are the responsibility of the institution's management. Our responsibility is to express an opinion on these financial statements based on our audit.

We conducted our audit in accordance with the auditing standards generally accepted in India. These Standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatements. An audit includes examining, on a test basis evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by the management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

We have obtained all the information and explanations which to the best of our knowledge and belief were necessary for the purpose of the audit. In our opinion, proper books of account have been kept by the head office of the above named society so far as appears from our examination of the books.

In our opinion and to the best of our information, and according to information given to us, the said accounts give a true and fair view:

(i) in the case of the Balance-sheet, of the state of affairs of the above named society as at 31st March, 2011 and

(ii) in the case of the Income & Expenditure account of the surplus being excess of income over the expenditure of its accounting year ended on that date.

The prescribed particulars are annexed hereto.

For D.K.A. Associates
Chartered Accountants



(D. K. Agarwal)
M.Com., LL.B., F.C.A., D.I.S.A. (ICAI)

Partner
Membership No. 071249

FCI 06054C

Place : Lucknow
Date : July 28, 2011

PEOPLE AT HFI

Management

President

Dr. Kanjaksha Ghosh

VP-Medical

Dr. Cecil Ross

VP-Development

Mr. Vikash Goel

VP-Finance

Mr. H. M. Sreedhar Rao

CEO

Rtn Wg Cdr (Rtd) SS Roychoudhury

Regional Council Chairman

RCC East

Mr. Ajoy Roy

RCC West

Dr. Devila Sahu

RCC North

Mr. Manoj Sharma

RCC South

Dr. Anburajan

Executive Committee Members

Mr. Kiranbhai Avashia, Mr. E. Raghunandan, Mr. Ambrish Kant Saxena, Mr. Kumar Shailendra, Mr. Rashid Lilani, Dr. Renu Saxena, Dr. Sudhir Kulkarni, Mr. Vinay Manchanda and Mr. Premroop Alva

CHAPTERS

Northern Region

- 1.Agra
- 2.Bareilly
- 3.Bikaner
- 4.Chandigarh
- 5.Delhi
- 6.Dehradun
- 7.Jaipur
- 8.Kanpur
- 9.Kupwara (Kashmir)
- 10.Lucknow
- 11.Ludhiana
- 12.Patiala
- 13.Panchkula
- 14.Srinagar
- 15.Varanasi
- 16.Yamunanagar

Eastern Region

- 1.Agartala
- 2.Bhadrak
- 3.Bhagalpur
- 4.Bhubaneswar
- 5.Brahmapur
- 6.Durgapur
- 7.Guwahati
- 8.Jamshedpur
- 9.Kharagpur
- 10.Kolkata
- 11.Patna
- 12.Ranchi
- 13.Rourkela
- 14.Siliguri
- 15.Tinsukia

Western Region

- 1.Ahmedabad
- 2.Aurangabad
- 3.Bhopal
- 4.Dhule
- 5.Goa
- 6.Indore
- 7.Jabalpur
- 8.Kolhapur
- 9.Mumbai
- 10.Nagpur
- 11.Nasik
- 12.Pune
- 13.Rajkot
- 14.Surat
- 15.Thane
- 16.Vadodara

Southern Region

- 1.Angamaly
- 2.Bangalore
- 3.Calicut
- 4.Cochin
- 5.Coimbatore
- 6.Davangere
- 7.Kadapa
- 8.Kannur
- 9.Karaikal
- 10.Hyderabad
- 11.Hubli-Dharwad
- 12.Kunnamkulam
- 13.Madras
- 14.Madurai
- 15.Mysore
- 16.Manipal
- 17.Pondicherry
- 18.Salem
- 19.Trichy
- 20.Tirunelveli
- 21.Trivandrum
- 22.Vijayawada
- 23.Vishakapatnam
- 24.Warrangal

EC MEETING ATTENDANCE SHEET (SEPTEMBER 2010 - JULY 2011)

Name	Date 26/9/2010	Date 18/12/2010	Date 26/3/2011	Date 16/7/2011	Percentage
Dr. K. Ghosh	P	P	P	P	100%
Mr.H.M.Sreedhar Rao	P	P	P	P	100%
Dr.Cecil Ross	P	P	A	P	75%
Mr.Vikash Chandraprakash Goel	A	P	A	P	50%
Mr.Manoj Sharma	P	P	A	P	75%
Dr.Anburajan	A	P	P	P	75%
Mr.Ajoy Roy	P	P	A	P	75%
Dr.Devila Sahu	P	P	P	P	100%
Mr.Kiran Avasia	P	A	P	A	50%
Mr.Vinay Manchanda	P	P	P	P	100%
Mr.E.Raghunandan	A	P	P	P	75%
Mr.Ambrish Kant Saxena	P	P	A	P	75%
Dr.Sudhir Kulkarni	P	P	P	P	100%
Mr.Kumar Shailendra	P	P	P	P	100%
Mr.Premroop Alva	P	P	P	P	100%
Mr.Rashid Lilani	P	P	A	A	50%
Dr.Renu Saxena	#	#	P	A	50%
Wg. Cdr. SS Roychoudhury	P	P	P	P	100%

Inducted in EC on 26.03.2011

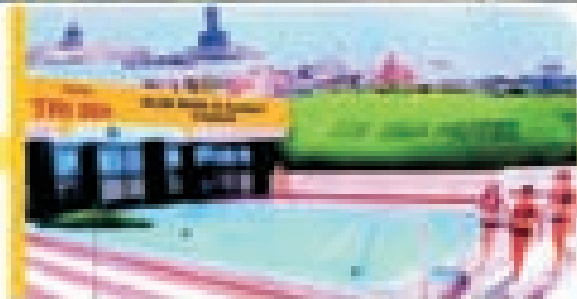


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TRI SEA

A/c. Non A/c. Rooms

(P) LTD



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CONFERENCE HALL AIR



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Deluxe DBL A/c Sea View

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Hotel Tri Sea Private Limited

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Phone: 04652 246586, Fax : 04652 248213, Mobile: 9442117474, 9442137474, 9487617474, 9487617474

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