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A quarterly bulletin on  
**Hemophilia**

Free Edition

# Hemophilia

## *Chronicle*

**One Country  
One Treatment**

**Hemophilia Without Disability,  
Children Free Of Pain**

Aurangabad Chapter organizing Awareness Program and Drawing Competition for the students and staff of New High School, Harsul, Aurangabad



**Hemophilia Federation (India)**

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# Regional Activities

## Northern Region

### Unify Hemophilia Federation (India) - Northern Region



On 18<sup>th</sup> & 19<sup>th</sup> January 2020, the 3<sup>rd</sup> KPT workshop under the NNHF Project took place at JRD Hotel, Safderjung Enclave, New Delhi. 40 participants, 2 from each northern chapter took the training on Advocacy, Chapter Compliances, and Digital Communication such as Facebook, Twitter and Instagram. The participants actively indulged in planning and setting their goals through group exercises.

The Key Person Training was highly successful in getting positive feedbacks for the content created and presented.

#### Dehradun Chapter **Heal-A-Soul**



On March 14<sup>th</sup> 2020, the chapter in association with BHEL-Heal-A-Soul project conducted a AHF distribution program at Hall of Tasmania University. Mrs. Richa Sharma (*BHEL-HR Head*) and Dr. S. Farooq (*patron*) were the special guests for the evening and they distributed AHF Kits to 9 PwHs from Haridwar District. 7 PwHs were Factor VIII deficient and 2 were inhibitors.

#### Jodhpur Chapter **Youth Meeting**

On 30<sup>th</sup> January 2020, the Chapter conducted their youth meeting where the Chapter's president provided guidance to

the youth members and the youth leader enlightened everyone about the efforts being made towards the patients with hemophilia.

During the meeting, it was unanimously decided that the youth participating in the coming AYM 2020 in Kolkata would ask for assistance from HFI to get hemophilia listed as a disability. If needed, they would collect the donation and file a petition in court to get hemophilia listed as a disability.

The youth group also discussed to meet the management of the



Pavata Satellite Hospital and discuss with them the issues like delay in getting the injection etc. and find a resolution together.

Mr. Suresh Takk from Nagor discussed with youth the future action plan to make factors available in Kuchera.

The youth members concluded the meeting by pledging that no matter how small our number is every youth member would dedicate their time and efforts genuinely.



## Eastern Region

### Unify Hemophilia Federation (India) - Eastern Region



**NNHF-HFI, India – 12 Project** was conducted at Hotel Atithi, Guwahati, Assam on January 25-26th, 2020. The Training covered important topics like Advocacy, Policy Making, Chapter Compliance, HCP Engagement and Communication & Social Media. The 2 days long workshop was a huge success where every chapter of the eastern region were invited and around 35 invitees from various chapters took part in it. The active participation of the chapter key-persons helped to achieve the objective of the workshop. The feedback received is an encouraging one, and all requested to conduct more such trainings in regular intervals. During the workshop the Republic Day 2020 also commemorated on 26th January 2020 by simply singing the National Anthem.

#### **Bhadrak Chapter Self-Infusion Workshop**



On 3rd February 2020, Biswajit Biswal, Nityananda Singh, Prabhat Ghosh & Mrutyunjay Senapati and other Youth group members of Bhadrak chapter organised a self-infusion and awareness camp at Basta CHC. Dr. Gatikrushna Panda was the Chief speaker of the program. A total 25 patients, some nurses took part in the event where self-infusion was taught and practiced under the supervision of physicians.

#### **Guwahati Chapter Meet and Greet Program of Youth Group**



On January 2, 2020, the Guwahati Chapter youth group organized a meet and greet program with its youth group in the premises of Guwahati Medical College and Hospital where they met Dr. Jina Bhattacharyya (HoD, Hematology Department, GMCH), Dr. Damodar Das (Hematologist, Hematology Department, GMCH) and other Doctors of Hematology Department of GMCH to convey their wishes and greetings for the New Year. They also conveyed their gratitude to other staff members.

#### **Regional Council Meeting and Key Person Training Workshop**



On 3rd February 2020, Biswajit Biswal, Nityananda Singh, Prabhat Ghosh & Mrutyunjay Senapati and other Youth group members of Bhadrak chapter organised a self-infusion and awareness camp at Basta CHC.

Dr. Gatikrushna Panda was the Chief speaker of the program. A total 25 patients, some nurses took part in the event where self-infusion was taught and practiced under the supervision of physicians.

#### **Ranchi Chapter Hospital Inauguration**



The chapter inaugurated their day care center at the district hospital in Giridih, Jharkhand. The program was attended by doctors, administrators,



MLA(Giridih) and PwHs/CwHs with their family members. The guests for the program were Dr. Sanjay Kumar Singh (Professor, Dept. of Medicines, RIMS, Ranchi), Dr. D. Munda (PMR, RIMS), Dr. Sidharth Sanyal (District Hospital, Giridih), Dr. Avdesh Pd. Sinha (C. S. District Hospital Giridih), Ms. Nidhi Verma (Hemophilia and Hemoglobinopathy SHG, Giridih), Ms. Mukta Mukta Jaiswal & Ms. Suvadra from HTC of RIMS. Once the program was concluded a CME for the doctors conducted and Prophylaxis treatment for nearly 30 CwHs was given by Dr. C. S. and Dr. Sanjay Kumar Singh.

## Women Day Celebration



On 8th March 2020, the chapter's women group celebrated International Women's Day and Holi Milan Samroha at their HTC, RIMS, Ranchi where all the female members of the PwHs/CwHs family participated along with doctors and media persons. The group also facilitated a discussion on the role of women in society. To conclude the program they played Holi.

## Siliguri Chapter Medical Education Program

On February 16, 2020, the chapter in collaboration with the



Durgapur Chapter organized a medical educational program highlighting the "Need of Physiotherapy in Hemophilia Management" and nearly 20 physiotherapists participated in the workshop from different hospitals of the North Bengal area.

The chief guest for the program was Dr. Pradip Kr. Mallick (Assistant Professor, Physical Medicine, Bankura Medical College & Hospital), and the Chief Speaker was Mr. Tapan Badyakar (Sr. Manager & Trained Physiotherapist in Hemophilia, SAIL-DSP Hospital, Durgapur).

## Western Region

### Unify Hemophilia Federation (India) - Western Region



**January 4 -5, 2020 | Pune:** The Key Person Training (KPT) workshop was organized for the western

region chapters of Hemophilia Federation (India) (HFI). 50 participants from 5 states namely, Chattisgarh, Goa, Gujrat, Madhya Pradesh and Maharashtra representing 21 chapters from the western region participated in this workshop. This workshop was organized with the support of Novo Nordisk Hemophilia Foundation, Switzerland (NNHF) under its India-12 project with HFI. This was Co-Facilitated by Regional Council Chair-West, Mr Ramu Gadkar, Mrs Indira Nair, and Mr Harshal Kale, who are the master trainers for the project. This capacity-building workshop was focused on Advocacy, Communication & Social media, Chapter compliances and Engaging with Hemophilia Care Providers at local and state level in alignment with Hemophilia Federation Indian's Advocacy goal, "One Country One Treatment".

## Aurangabad Chapter Awareness Program



The chapter's youth group organized an awareness program and drawing competition for the students and staff of New High School Harsul Aurangabad. The chapter started a chain of distributing plant sapling to the participants with the objective of saving the environment.

## Physiotherapy Camp

The chapter organized a physiotherapy camp for its PwHs/CwHs in collaboration with Aurangabad District Civil Hospital. The program aimed to provide guidance and information on Physiotherapy and its role in Hemophilia. The session was

conducted by Senior Physiotherapist Dr. Prachi and Dr. Ashish.

## Makar Sankranti Celebration

On January 15, 2020, the chapter's women organized a program to celebrate Makar Sankranti where approximately 50 women participated. The women group discussed the guidelines of management of CwH and also provided counseling to women suffering from mental stress due to the care and management of CwH.

## Ahmednagar Chapter Success Story



Mr. Mahesh Shelke, 28-year-old Factor-VIII deficient PwH, qualified the SET examination in August 2019 & NET-JRF examination on 31st December 2019 and is now eligible for the post of Assistant Professor in Journalism and Mass Communication.

He belongs to a lower economic

background and comes from a remote place near Ahmednagar. He belongs to Ahmednagar Chapter. HFI applauds the success of Mr. Mahesh Shelke. His success story shall inspire other C/PwHs.



**Mehsana Chapter**

**Inhibitor Screening Program and AGM**



On February 16, 2020, the Chapter organized an inhibitor screening program and the Annual General Body meeting in collaboration with Civil Hospital, Mehsana. In this program, nearly 183 participants attended including 97 patients of the hospital. The special guests were Dr. Dinesh Vyas, Dr. Nimesh, Dr. Dinesh Amin (HoD, Pediatric Dept.), Dr. Rajendra Trivedi (HoD, Dental Dept.), Dr. Varsh Chaudhary (Physiotherapist) who shared information with the participants on Hemophilia. Further, a prize distribution ceremony was organized to motivate the PwHs.

**Pune Chapter Makar Sankranti Celebration**

On January 19, 2020, the chapter's women group celebrated the festival of Makar Sankranti. The women group invited Mr. Rashid for his guidance and advice on entrepreneurship. He encouraged and appreciated the women group and also shared ideas with them to help their entrepreneurship skills. Furthermore, he assured to set up a small shop to help the group under the Bachat Gat scheme.

**Panaji Chapter**

**Education Program**



On February 22, 2020, the Chapter's youth group conducted a Nurse Education Program and Occupational Therapy in Hemophilia Care session at JMJ Hospital, Porvorim. Dr. Vinayak Bhat shared about the new rules of the treatment centre, and Dr. Parag Adsule educated the participants on occupational therapy and how it can be useful for a PwH to lead a healthy life.



**Southern Region**

**Bidar Chapter Executive Committee Meeting**



Haemophilia Society Bidar Chapter held a Executive Committee Meeting. In this meeting we discussed about bringing a new HTC.

**Hyderabad Chapter Youth Meet**

On 1st January 2020, the Chapter's Youth Committee organized a Youth Awareness program at the conference hall of Little Stars Hospital where 13 young PwHs participated in the program. A special session on Emicizumab was also organized where they

discussed its Pros and Cons, Psychosocial issues caused by having a chronic condition, it's effects on Pwhs lives. The program also included teaching self- infusion to the participants and sharing with them the importance of Physiotherapy.





## Kunnamkulam Chapter

### Family Get-Together



On 16th February 2020, the Chapter organised a family get together for its members at Kannan Memorial Charitable Trust Hall, Akkikkavu. The program was inaugurated by Dr. Ninan Koothoor (President, IMA Kunnamkulam). During the program, discussion about the crises faced by PwHs in Kerala was discussed. Sri E.Raghubandan highlighted that the Govt. of Kerala may discontinue Karunya Project which may lead to unavailability of AHF which may lead to a rise in disability and mortality rate. Later a dental camp and physiotherapy session by Dr. Sushanth B and Mr. Babu K.M was conducted respectively.

A session was conducted by Adv. Rema Raghubandan wherein he explained the causes of increasing stress among Pwh and also took a counselling session for participants.

## Vijayawada Chapter

### Annual General Body Meeting and Patient Awareness Program



On 2nd February 2020, the Chapter conducted its Annual General Body Meeting, Patient Awareness Program & Educational Program" at Sir C.R. Reddy Autonomous Degree College, Auditorium, Eluru where 500 members along with their families participated in the program.

A detailed discussion was conducted on making factors available at all government institutions to address the upcoming

treatment modules for hemophilia in the region.

The guest for the programme was Mrs. Usha Parthasarathy (SOL, Program Coordinator), Mr. J Satya Narayana Raju (Dhamma Vijaya Vipassana Meditation Center), Dr.J. Udayraj (Physiotherapist, Little Stars Women & Child Hospital, Hyderabad) & Dr Mukherje Dande (Physiotherapist).

Interactive session on Hemophilia Care & Management by Dr M.B.S.V. PRASAD (Secretary, Vijayawada Chapter), Role of Physiotherapy by Dr. J. Udayraj (Physiotherapist, Little Stars Women & Child Hospital, Hyderabad) & Dr Mukherje Dande, (Physiotherapist, Vijayawada), Yoga & Meditation by Mr. J. Satya Narayana Raju was also held for the participants.

Mrs. Usha Parthasarathy (SOL, Program Coordinator) distributed 2nd quarter scholarships.

## Visakhapatnam Chapter

### Self- Infusion Training Program



On 5th January, 2020, the Chapter organized a self-infusion training program in the premises of Dr. Chandra Sekharam Clinic. Mrs. Rajeswari who is working as the nurse in the clinic shared information about nerves, it's types and how they work and then taught self-infusion to the participants. Later she asked the PwHs and their parents to try the self-infusion and most of them succeeded in the first attempt. In the end of the training the participants shared that they were feeling confident about the self-infusion.





## Self- Infusion Training Program



On 26th January 2020, the Chapter conducted its second self infusion training in the premises of Dr. Chandran Sekharam Clinic where Mrs. Rajeshwari(Sr. Nurse) guided and educated the participants on self infusion techniques and later she asked the participants to try it themselves.

## World Federation of Hemophilia's visit to HFI



The WFH team comprising of Mr. Mark Skinner, Dr. Assad Haffar, Mr. Hans Jacques and Mr. Ravi Pratap (BSI) visited the HFI Delhi Headquarters on January 8th 2020 and January 9th 2020. The meeting was also attended by Mr. Vikash Goyal (President, HFI), Wg Cdr SS Roy Choudhury (CEO, HFI) and Mr. Pawan Madhukar (Manager, Communications).



The team paid the visit to reinforce their support to HFI and also to observe the Quality Management System implementation in the HFI module. On the first day of the meeting Mr. Pawan Madhukar shared the implementation of QMS through a presentation and together the team discussed the best ways to implement the QMS effectively in HFI.



## OBITUARIES



### Late Mr. Manush Kumar

Aged 35 Years,  
Severe Hemophilia A Patient  
Died on 23<sup>rd</sup> February 2020  
Member of Hemophilia Society Cochi Chapter



### Late R. Srinivasa Rao

Aged 13 Years, Hemophilia A  
Died on 30<sup>th</sup> March 2020 due to IC Bleed. Member of Hemophilia Society Visakhapatnam Chapter



### Late Mr. Fakir Chand

Aged 35 Years, Hemophilia A  
Died due to severe bleeding in the throat and chest because of injury. Hissar, Haryana



### Late Mr. Ashutosh Sapathy

VwD Patient, Died due to head injury.  
Member of Hemophilia Society Bhubaneswar Chapter

**We express our deep sorrow on the sad demise of our beloved friends. May their souls rest in Peace and may God give strength to their family members for this unbearable loss.**

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Don't let their dreams  
**bleed inside**

In **haemophilia**,  
internal bleeding  
leads to **disability**  
**in 8 out of 10**  
youngsters<sup>1</sup>.



Let their dreams  
**BECOME A REALITY**

**Think Prophylaxis** - The  
proven measure to prevent  
disability among patients  
with haemophilia<sup>2</sup>

## Our commitment to disability-free haemophilia in India

**Medicines**  
Innovation & High  
Quality Supply

**Healthcare  
Community**  
Scientific Dialogue &  
Sustainable Access

**Patients**  
Education &  
Support Programs

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