novo nordisk haemophilia foundation

A journey to systemic change

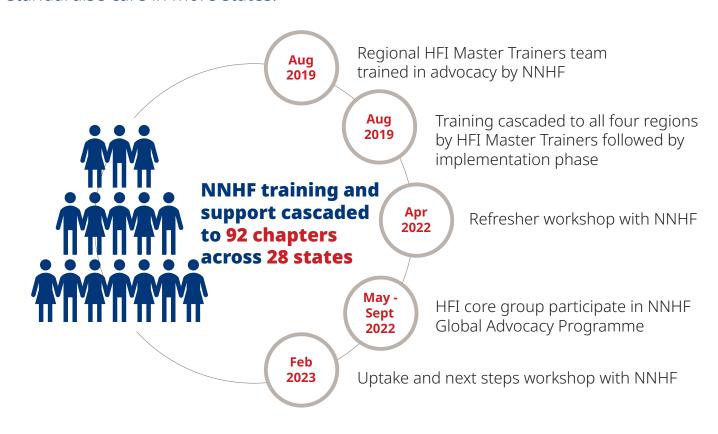
Hemophilia Federation (India) advocacy initiatives supported by the Novo Nordisk Haemophilia Foundation

Working in partnership since 2013

The NNHF has supported HFI through six programmes over the last ten years. The partnership has evolved, moving from regional or state-led initiatives to those which consider a national strategy, whilst maintaining a state-led implementation approach. In 2019, the NNHF supported the first programme which focused on advocacy. The following pages highlight some of the achievements of HFI and its chapters that this has contributed to.

Unifying HFI to advocate for standardised national care

Through ongoing dialogue between the NNHF, HFI Master Trainers and HFI chapters, systemic change has been achieved at both state and national level. The HFI and NNHF will continue to work together on a newly approved project, which integrates this advocacy model with the medical community's efforts to standardise care in more states.



50% of states have seen a systemic change since 2019



CHF 3.6m

1

~20%

increase in national budget allocation for bleeding disorders

ADVOCACY UPTAKE HIGHLIGHTS

As of June 2023, 14 states have seen at least one advocacy uptake due to their advocacy efforts since 2019. Here we highlight a small selection - see the map for more examples.

Improved treatment availability in Odisha

Inclusion of treatment in the Essential Drugs List (EDL) is a key milestone in improving access to care, as the treatments listed are intended to be procured on priority. This is exactly what HFI achieved in Odisha, where recombinant factors are now included in the EDL and available in hospitals throughout the state.



Access to government support in Rajasthan

Whilst haemophilia has been recognised as a disability since 2016, in 2022 Welfare Hemophilia Society laipur organised an awareness and planning programme with the National Health Mission, where many people received disability certificates offering maximum level of support. As well as providing pensions and travel support, people like Gaurav Soyal can now access crucial educational benefits such as scholarships and support in written exams.





New facilities in Karnataka

Diagnosis is the starting point to access to care. It provides the data needed to procure sufficient treatment and engage authorities. In Karnataka, ongoing engagement between HFI, state authorities and hospitals resulted in eight new diagnostic facilities being established – a higher number than some of the larger states. Additionally, Karnataka was the first state to provide free treatment and one of the first to distribute it at district level.

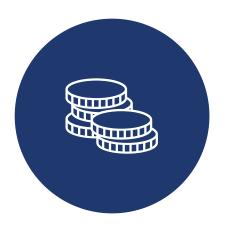
Systemic change in India: Map of selected highlights

In April 2023, the NNHF and HFI worked together to collect examples of advocacy uptakes achieved across all states since 2019.



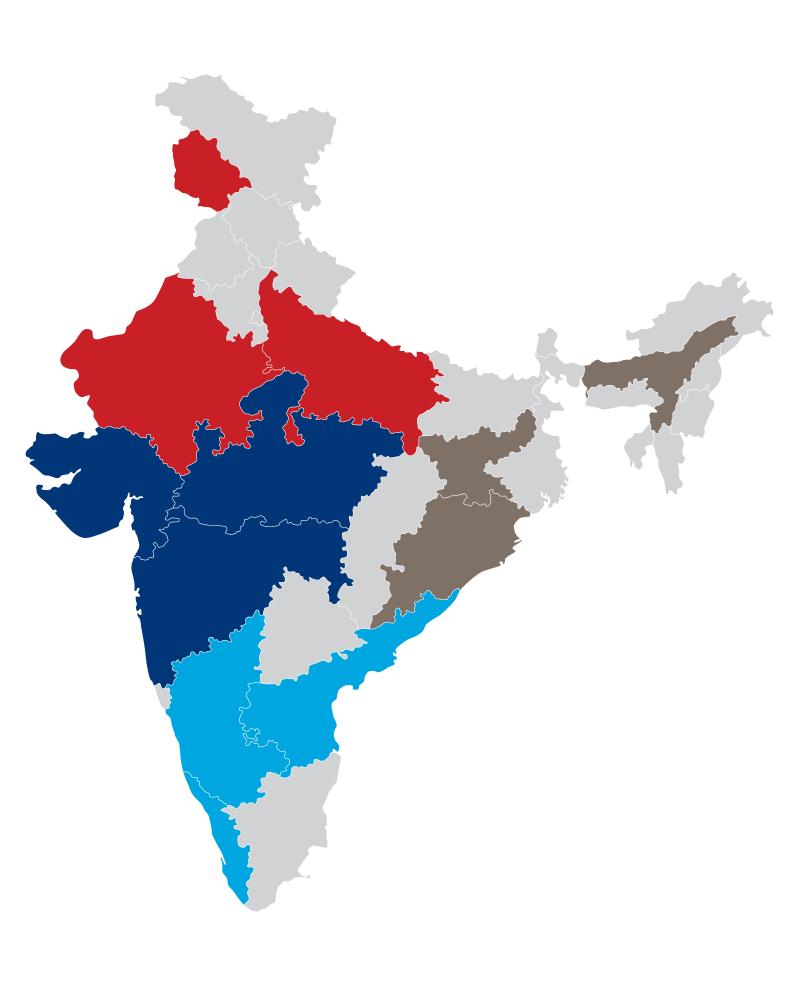
NORTH

- Jammu and Kashmir: 103% budget increase
- Rajasthan: Procured factor available in all 33 district and disability certificate issued
- Uttar Pradesh: Procured factor is now available in 26 centers



WEST

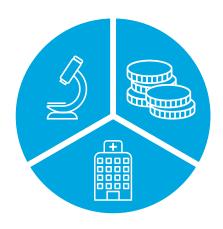
- Gujurat: 24% budget increase
- Madhya Pradesh: 100% budget increase
- Maharashtra: 40% budget increase





EAST

- Assam: Home prophylaxis started for more than 200 people
- Jharkhand: Eight new Haemophilia Treatment Centres procuring treatment
- Odisha: Factors added to Essential Drugs List



SOUTH

- Andhra Pradesh: 9 more districts with Haemophilia Treatment Centres
- Karnataka: 8 new diagnostic facilities and factor available in all districts
- Kerala: 59% budget increase
- Tamil Nadu: 276% budget increase

