

Project:  
India 2

**Together  
delivering  
life-changing  
impact**

Outreach activities conducted through the India 2 project will benefit families in Karnataka, such as the Kumar family from Manipal.



novo nordisk  
haemophilia foundation



A summer camp in 2013 teaches patients the importance of physical activity.

### The challenge

In 2011, throughout the region of Manipal, there were **numerous people living with haemophilia in rural areas**. These people had virtually **no access to care** and were entirely **isolated**.

### The achievements

**673 healthcare professionals were trained** throughout the region, a network of **2760 ASHAs** (community healthcare workers) were activated to provide outreach, **150 patients were newly diagnosed**, and **585 patients and caregivers attended community events**.

Partner: Kasturba Hospital, Manipal University Represented by: Dr Annamma Kurien, Associate Dean, Professor of Pathology Start/end date: Q4 2011–Q1 2016

## India 2: The remarkable power of an IDEEA

India presents an interesting dilemma for haemophilia care.

Factor is available. The country supports factor for people diagnosed with haemophilia. However, there are still many people who go without treatment. In the region of Manipal, patients faced many barriers:

- Healthcare professionals in the public hospitals had very little knowledge or awareness of haemophilia – making it unlikely that a patient would be diagnosed with the condition
- Most patients are located in rural areas with difficult access and few health care units
- Very few hospitals had the capability to perform the necessary tests to diagnose haemophilia.

Dr Annamma Kurien set out to address these challenges. And she did so by finding a way to work within the existing healthcare system. The project was all based on a very simple IDEEA.

### A big IDEEA

IDEA (Identification, Diagnosis, Education and Empowerment for Action) is a 3-year project to improve the quality of life of patients with bleeding disorders in South India. It is an ambitious initiative that combined healthcare professional training, strategic outreach, and patient empowerment so that people with haemophilia can receive adequate care and live better lives.

The project worked on four separate fronts.



A specialised coagulation testing facility was set-up at Kasturba Hospital, Manipal University.

### **Front 1: Healthcare professional training**

Intense training initiatives were launched in all four districts (Udupi, Dakshina Kannada, Chickamangaluru and Shimoga). Workshops and seminars were conducted for healthcare professionals in centres that provided primary care, as well as secondary care centres.

Led by Dr Sukesh Nair, Professor of Clinical Pathology, CMC Vellore, the project team led a 4-day, hands-on workshop on coagulation that trained doctors and laboratory technicians.

These combined efforts resulted in the training of 553 doctors, 51 nurses, 51 physiotherapists, and 18 lab technicians. This created a foundation of healthcare knowledge across all four regions.

### **Front 2: Training of ASHA mentors and ASHA workers**

ASHA workers are a network of local community healthcare workers that are utilised throughout India. Utilising this network to expand haemophilia care was a critical part of the project's success.

First, a haemophilia nurse trained key ASHA workers, who then passed on the training to their colleagues throughout the 4 regions. The training focused on creating awareness of the symptoms of haemophilia, so the ASHAs could identify patients suspected of having a bleeding disorder and refer them to the relevant specialists.

Once the training was successfully rolled out, the ASHAs engaged in a door-to-door survey of areas within their territory. They distributed educational materials, gained information about newly identified patients and families, and put people with haemophilia in touch with the relevant healthcare services. This led to getting effective health records for patients who until then had received little or no care.

This ASHA-based part of the project resulted in 2,760 ASHAs and Auxiliary Nurse Midwives trained, 2,785 educational pamphlets distributed, and 2,594 patient records updated or created.

### **Front 3: Laboratory diagnosis**

With many new patients discovered and new documentation coming in, it was necessary to upgrade the testing capability of the region. The project team and NNHF created a specialised coagulation testing facility at Kasturba Hospital, Manipal University. The upgrade included the installation of new technology, more accurate reagents, and staff training.

Once established, this new laboratory was able to serve the four regions. Patient testing, re-testing, and diagnosis was conducted to great effect. 594 people were tested and 150 new patients were diagnosed.



Community workers were trained to identify the symptoms of haemophilia.

#### Front 4: Empowerment for action

Dr Kurien and her team knew that it is not enough to only address haemophilia on the healthcare professional level. No matter how advanced the healthcare facilities, it will not be successful if the patients are not engaged in their own care. For this reason, great efforts were made to bring these patients together and begin to create a true haemophilia community.

- Summer camps for patients and their families were organised. The camps focused on providing patient education, empowerment, bonding and a sense of wellbeing. One highlight was a cricket match between patients and famous players as Mr Syed Kirmani. Other deeply moving activities were motivational speakers such as Paralympics medallist and Arjuna award winner Dr Malathi Holla.
- Caregiver support groups were organised to provide support for the women who care for haemophilia – a group whose struggles often go unrecognised and unsupported.
- Educational materials, social support materials, and treatment log books were widely distributed

In total, 435 participants attended the haemophilia camps, 30 women came together in support groups, and 226 families received much-needed educational materials. When you consider that these patients and caregivers were largely isolated before this project began – these numbers are truly remarkable.

#### In conclusion: An IDEEA that goes beyond the project itself

The IDEEA project is more than a project. It serves as a model that can be replicated throughout India. Dr Kurien and her team have proved that isolated patients can be reached – and their lives can be dramatically improved. For these reasons, and in recognition of the project team's excellent project management skills and stakeholder engagement, the project was awarded the 2014 NNHF Project of the Year Award (see the NNHF Activity Report 2013/2014 for more information).

This project affected many people with haemophilia in the Manipal Region. But the hope is that it will eventually affect people all across India.



Visit [www.nnhf.org](http://www.nnhf.org) for more information about all NNHF programmes  
[www.facebook.com/novonordiskhaemophiliafoundation](https://www.facebook.com/novonordiskhaemophiliafoundation)



Nurse Sulochana supported the training of community workers and attended visits to families in rural areas.



Project partner Dr Annamma Kurien receiving the NNHF 2014 Project of the Year Award with Nurse Sulochana.

## Steps to Success: The Anatomy of IDEEA

**The creation of cross-sector partnerships between patients, healthcare professionals, authorities and other stakeholders was a vital element of this project, in terms of ensuring sustainable access to care.**

The success of the initiative has led authorities to consider the integration of this approach into the care offering on a provincial level, comprising the following components.

1. Establishment of a hospital hub at a tertiary level which provides training and support to a network of partnering secondary and district level hospitals.
2. The inclusion of bleeding disorders in the ASHA workers' curriculum, so they can identify and educate people with bleeding disorders.
3. Provision of quality coagulation testing, meaning providing screening test at secondary and district level, and specialised tests at hub level.