In 2013 in Egypt, patients in the city centres had access to knowledgeable healthcare professionals and the support of an active patient association with strong leadership in place. But it was a different situation outside of these areas.

Dr Magdy El Ekiaby and The Egyptian Society of Haemophilia (ESH) recognised this critical need and wanted to do something to change it. The result was an ambitious project entitled: ‘Empowering the haemophilia community in Egypt’.

Laying the groundwork
The team methodically started arranging a series of ‘caravans’ – educational outreach visits to different regions. These caravans were a way to increase knowledge and awareness about haemophilia and its management in the regions, as well as to bring together key stakeholders in haemophilia care – in particular the patient and healthcare professional communities.

Based on population distribution and after demonstrating motivation and interest in developing haemophilia care, Alexandria, Al-Mansura, Asyut, Faiyum, Ismailia, Qena and Zagazig were the seven cities identified as locations for the caravans.

Taking knowledge on the road
Each caravan included an extensive team of experts. Experienced haemophilia healthcare professionals, trainers, and key leaders from the ESH went on the road to the individual regions. They conducted a series of meetings and working sessions that brought together local people with haemophilia, their families, local healthcare professionals as well as authorities and community members.

The challenge
Haemophilia care in Egypt began in the 1960s, and 50 years later is established in Cairo and some major cities.

However, in 2013, efforts were needed to ensure care was also available to people living outside of these cities. To achieve this, training and education for healthcare professionals and patients was needed, together with a united patient and medical community, to address and engage healthcare authorities with one voice.

The achievements
7 haemophilia caravans visited 7 regions and delivered training to over 500 healthcare professionals and over 300 patients and family members. Treatment guidelines were established to standardise care and 4 physiotherapy clinics were established to reduce joint damage. Healthcare professionals and patients started working together to set joint goals and plan future activities, and patient leaders were trained to strengthen the patient association.

Partners:
The Egyptian Society of Haemophilia (ESH) Represented by: Dr Magda Rakha and Dr Magdy El Ekiaby

Egypt: Caravans to empowerment

Prof Adly Sabbour at a physiotherapy session in Qena.
During the caravans, they distributed educational books that explained the facts about haemophilia management and provided simple physiotherapy tools. Local emergency units were given posters describing how to identify acute bleeds and what steps to take. Materials were in both Arabic and English to ensure maximum receptivity.

As well as providing practical knowledge, the working sessions during the caravans provided the opportunity for open discussions between the patient association, patients and authorities.

The impact on awareness and care
In total, the caravans delivered remarkable results. More than 300 physicians, 160 nurses, 50 lab technicians, 6 physiotherapists, 220 people with haemophilia, and 120 family members attended the events. The open forum meetings among these stakeholders established a new understanding of what is needed to manage haemophilia – and the interconnected role of the entire community.

Patients were able to voice the challenges they faced and establish a network to help them. Dr Sonia Adolf, patient association member and one of the organisers, described the caravans by saying: “They started to exchange their experience, ideas and they also tried to find a way to solve their problems while working together.” The caravans truly lived up to their aspiration of creating empowerment.

“As patients we only see our problems, but it’s now a chance for us to communicate with different provinces and learn, share experiences and find solutions. The caravan is very important for us as they invited people from the Ministry of Health, health insurance and the university. Putting them all together on one table talking about haemophilia is something we have dreamed about,” said a patient from the Faiyum caravan.

For healthcare professionals, they too developed a new level of awareness. Beyond basic knowledge of haemophilia care, they were able to establish relationships with the team in Cairo, who were an invaluable resource to continue increasing their haemophilia knowledge.

With the engagement of healthcare authorities, support has been gained to establish four physiotherapy centres through the project – two in Cairo and one each in Alexandria and Asyut, with training being delivered by Prof Adly Sabbour.

Finally, the healthcare authorities were able to see first-hand the great need that exists in haemophilia care. The project built the basis of a stronger registry in Egypt that includes all regions. Treatment guidelines have been approved by the national health insurance, which will lead to standardised care in future. All of these activities contributed to a dramatic increase in the factor supply – moving from 14 million units in 2013 to 30 million units in 2014.

The impact on community
In seven regions throughout Egypt, the caravan has come and gone – but the haemophilia community has started a journey of unity and empowerment that has the potential to take haemophilia care in Egypt to new places. Alongside the World Federation of Hemophilia and other organisations, we look forward to being part of this journey and working to improve care in other regions across Egypt – starting with the development of musculoskeletal care.

Projects › Egypt

Preparation of a caravan – engaging the right stakeholders
To ensure the caravans brought the right people together, the project team established contact with patients, key healthcare professionals, the local healthcare authority and local university or medical school to create further interest in the project as well as establish a location for the caravan event to be held.

Bringing all of these people together in one place for the caravans brought many benefits:

- The authorities from Cairo, who are responsible for decision-making at a national level, saw the reality of haemophilia care outside of the capital city. One example is that they saw that the hospitals which had supplies of treatment did not have the trained healthcare professionals to use it, and likewise, those healthcare professionals who had the skills to administer treatment were based in hospitals which did not have supplies. The authorities are now working to ensure all hospitals have both a supply of treatment as well as trained healthcare professionals.

- Authorities were able to hear what challenges patients faced, directly from the patient. This led to the authorities developing ways to try to improve access to care for these patients, including introducing haemophilia care to Faiyum and home treatment being introduced in the Red Sea governance, according to Dr Nagla Shahien from the national health insurance office.

- Involving patients and giving them a share of voice was vital in building relationships between them and the medical community. The caravans were a platform for patients to express their concerns. This led to youth leaders being identified, who then underwent leadership training to help harness their skills and convert their passion for their rights into empowerment for the whole community, and with that becoming part of the solution to better access to care.