

REGIONAL HEMOPHILIA PROJECT IN TURKEY

Zülfikar B^{1,2}, Büyükpınarbaşı Y², Kılıcoğlu O³, Ak G⁴, Koc B¹, Berber E⁵, Ozdemir N¹, Ovalı F⁶, Turkmen C⁷, Zulfikar H⁸

¹Istanbul University, Cerrahpasa Medical Faculty and Oncology Institute, Department of Pediatric Hematology/Oncology, ²The Hemophilia Society of Turkey

³Istanbul University, Istanbul Medical Faculty, Department of Orthopedics and Traumatology, ⁴Istanbul University, Dentistry Faculty

⁵Istanbul Arel University, Department of Molecular Biology and Genetics, ⁶Istanbul Medeniyet University, Department of Pediatrics

⁷Istanbul University, Istanbul Medical Faculty, Department of Nuclear Medicine, ⁸Istanbul University, Faculty of Economics

BACKGROUND

- All people do not have the same facilities and could not contact with medical staff in emergent countries.
- The Hemophilia Society of Turkey (TrHD) is the important NMO in their region which has connection with WFH.
- The purpose of TrHD is provide the same facilities all over the country.
- All hemophiliacs all over the country can be educated by the medical staff who are experienced about hemophilia. This project provides education and medical support to the people with hemophilia. , relationship between people with bleeding disorders.

OBJECTIVES

- The main purpose of this project is to educate people with hemophilia (PwH) who are far from the centres, to evaluate patients in a multidisciplinary team and solve the problems of PwH in other regions of Turkey.
- So PwH are going to manage to reach the Comprehensive Care Centre.

PROJECT

- Three Regional Hemophilia Symposium organized by the Hemophilia Society of Turkey (TrHD) at Marmara Region (Yalova), Eastern Turkey (Diyarbakır) and Northern Region (Rize). Patients, their relatives, doctors and nurses participated.
- The project consist of education, patient examination by Hemophilic Arthropathy Council that includes dentist. At first, two of the doctors made general examination of patients. Then, the scientific program was held in two separate sessions. Hematologists, orthopedic surgeon, nuclear medicine expert, dentist and genetic expert gave information about hemophilia. In the last part of the symposium patients were evaluated by Hemophilic Arthropathy Council.
- In Yalova; 28 patients had general examination and 9 examined in Hemophilic Arthropathy Council. In Diyarbakır and Rize; 41/11 patients had general examination and 14/4 examined in Hemophilic Arthropathy Council.



CONCLUSION

- This project is important milestone for all over Turkey. It provides evaluation of PwH in multidisciplinary team and also relationship between patients who go from comprehensive care centre (CCC) and who live far from CCC or could not reach CCC. Also people provide psychosocial support each other at the CCC who have problems.
- The Hemophilia Society of Turkey intends to continue this project in other regions of Turkey and neighbour countries. However, the results of similar projects should be evaluated in an international environment.

