

# SCHOOLS OF FAMILIES FOR PARENTS OF CHILDREN WITH HAEMOPHILIA



Inmaculada Perez-Galindo<sup>1</sup>, Ana Torres-Ortuño PhD<sup>2</sup>, Manuel Moreno-Moreno<sup>3</sup> & Emilio Miñano-Garrido<sup>4</sup>

1. Social Worker. ARMH. Murcia (Spain). 2. Dept. of Psychiatry and Social Psychology, University of Medicine. Psychologist ARMH, Murcia, (Spain). 3. Hematology Service, University Hospital Virgen de la Arrixaca, Murcia, Spain. 4. Physiotherapist ARMH. Murcia (Spain)



## INTRODUCTION

The ARMH was created in 1977, in order to provide a comprehensive treatment of the disease for those affected by hemophilia and their families in Murcia (Spain). One of their activities is to provide parents of children with haemophilia, especially newly diagnosed or parents with young children, information and training about the disease and its treatment. It represents a good child development and family functioning. Consequently, a good quality of life in spite of the disease.



## OBJECTIVES

To inform and educate parents through theoretical and practical workshops on hemophilia and its treatment. We use a view medical, psychosocial and musculo-skeletal

## MATERIAL AND METHODS

The program is.: theoretical and practical workshops on hemophilia and its treatment (biopsychosocial approach). The sessions are: development: learning self-treatment technique (4 workshops), emotional support (2 workshops), hemophilia: treatment and proper use of the factor (2 workshops) and physical exercise and arthropathy prevention (2 workshops). It involved

12 families who come to the Association (2h 30m). Health professionals treat the issues. Meanwhile, children are carry out recreational activities with volunteers and other of them get involved with his parents in the workshops.



## RESULTS

The results (see table 1) show us that this activity is satisfactory for parents. We could say that it encourages parents to assimilate the situation and they will adapt to it gradually

<b>Self-treatment technique</b>	100% parents have tried to make or practice it	65% parents have learned it	35% parents need more practice (they still have some fear)
<b>Psychosocial issues</b>	65% parents got emotional stability and learned appropriate coping strategies	25% parents reduced their fears and start to adjust to the situation	10% parents continue with some anxiety and difficulties of adaptation
<b>Basic Medical concepts</b>	80 % parents have a good knowledge of disease and its treatment	15% parents have a regular knowledge	5% parents are still starting in the new situation
<b>Physiotherapy and Physical Exercises</b>	50% of children do exercise regularly	35% of children practice exercise sometimes	15% of children do exercise only when they have a problem



## CONCLUSIONS

This type of project from the Hemophilia Associations we believe is an important step in getting people with hemophilia are integrated in a similar manner to any person without disease

## REFERENCES

- Alderfe, MA, Fiese, BH, Gold JI, & al. Evidence-based Assessment in Pediatric Psychology: Family Measures. *Journal Pediatric Psychology* .2008; 33(9): 1046-1061.
- Coppola A, Cerbone Am, Mancuso G, Mansueto MF, Mazzini C, Zanon E. Confronting the psychology burden of haemophilia. *Haemophilia* 2011.17(1):21-7.
- Emiliani F, Bertocchi S, Poti S, Palaretu L. Process of normalization in families with children affected by hemophilia. *Quality Health Research* 2011. 21(12): 1667-78.
- Knafelz KA, Damey BG, Gallo AM & Angst DB. Parental Perceptions of the Outcome and Meaning of Normalization. *Research Nursing Health*. 2010. 33(2): 87-98