

# Twinning programme between the Panamanian Foundation of Hemophilia and the Catalan Association of Hemophilia



Felipe Ortega, Patricia Cabré  
Associació Catalana de l'Hemofília  
info@hemofilia.cat



Alaisa Aráuz de Melgar, Luis Melgar, Yudiana Montenegro  
Fundación Panameña de Hemofilia  
funpa\_hemofilia@hotmail.com

## Introduction

Members of the Catalan Association of Hemophilia (ACH) and the Panamanian Foundation of Hemophilia (FPH) met in a workshop organized by the World Federation of Hemophilia in 2002.

As a result, a friendship was born and thanks to the projects of the WHF, it became a twinning programme, which lasted for three years (2008 to 2011).

## Objectives

The collaboration between the FPH and the ACH was born with great illusion and in the hope that the Panamanian Foundation of Hemophilia could operate perfectly, once the twinning programme finished.



With Health Ministry representatives



With young FPH members

## Description

Some of the areas of collaborative work were:

- Organization of the FPH office
- Knowledge of the community
- Design of attention programmes
- Training and assessment for professionals linked to the FPH
- Relationships with the health authorities
- Funding of financial resources

## Conclusions: hope becomes reality

We have managed to improve the functioning of the office by opening daily and for this reason the projects can be followed up and the immediate needs of the community are dealt with. The equipment and the use of new technology have been improved.

Certain income has been guaranteed thanks to the use of a photocopying machine.

A database has been elaborated to manage the census and they are carrying out a house to house study to detect the community needs, improving the relationship with its members.

For the first time, in 2009, an annual project was designed to support different activities.



With Hospital del Niño medical staff

In 2009 two workshop seminars were organized, one for families and another for professionals. The board members were given specific training related to associative tasks, too.

In 2010 a workshop was done for teenagers and young people.

Great achievements have been reached with the Health authorities: Hospital del Niño became officially known as the National Centre of Hemophilia in Panama for Pediatrics.

