

# Changes in hemophilia treatment in Bolivia after joining the World Federation of Hemophilia (WFH)

Gerardo F. Rojas Alba

Hemato-oncologist, Children's Hospital Dr. Mario Ortiz Suarez - Santa Cruz, Bolivia

## INTRODUCTION AND OBJECTIVES

Bolivia has an underdeveloped health care system, which offers limited coverage for the wider population. It is estimated that given a population of 10.5 million, 1000 patients have hemophilia A and 200 patients suffer from hemophilia B. For many years there has been a lack of diagnostic laboratories, specialized health centers, professionals, medicines, and proper regional organization, along with little knowledge of the disease. The Children's Hospital is a national center of reference where patients with hemophilia are treated. Since 2010, Bolivia is part of the WFH and receives support to improve hemophilia care.

## METHODS

A retrospective analysis was performed, based on the clinical data of outpatients and inpatients from 2009 to 2012. The WFH donated factor concentrates, organized lectures and training courses for health care personnel, and encouraged the participation in a twinning program.



## RESULTS

Following changes were identified:

- ✓ Increased number of patients who were under-diagnosed
- ✓ Increased number of medical controls
- ✓ Creation of the Hemophilia National Organization with regional representatives
- ✓ Increased use of factor concentrates
- ✓ The government started to create a program for national care of bleeding disorders including hemophilia
- ✓ Lower incidence of bleeding complications
- ✓ Support to specialized centers from neighbor countries through twinning programs

**1er. SIMPOSIO TALLER ATENCIÓN DE LA HEMOFILIA**  
Miércoles 20 de noviembre 2013  
9:00 a 12:00 y 14:30 a 18:00  
Lugar: Ministerio de Salud y Deportes  
Plaza del Estudiante - La Paz

**TEMAS**

- FISIOLOGÍA DE LA HEMOSTASIA
- GENÉTICA CLÍNICA Y DIAGNÓSTICO DE LA HEMOFILIA
- MANEJO DE LAS EMERGENCIAS EN HEMOFILIA
- COMPLICACIONES CRÓNICAS DE LA HEMOFILIA
- COMPRENDIENDO QUÉ ES LA HEMOFILIA
- ADMINISTRACIÓN DEL FACTOR
- HEMOFILIA EN PEDIATRÍA
- TÉCNICAS DE ENFERMERÍA
- EMERGENCIAS HEMORRÁGICAS EN EL HOGAR
- LA FUNDACIÓN: OBJETIVOS ALCANZADOS, PROGRAMAS Y PROYECTOS

**DÍA MUNDIAL DE LA HEMOFILIA 2013**  
7 DE ABRIL DE 2013

**Primer Taller de Hemofilia**  
18 y 19 de mayo de 2013 - Trinidad  
Hospital Materno Infantil (Av. Japón)

**Temas:**

- Fisiología de la coagulación
- Trastorno hemorrágico
- La hemofilia y su tratamiento
- Manejo multidisciplinario
- Reseña de la fundación
- Objetivos alcanzados
- Programas
- Eventos y Proyectos nacionales

**Inscripción Bs 30**

**Disertantes:**

- Dr. Gerardo Rojas Alba**  
Asesor Médico  
Fundación Nacional de Hemofilia Bolivia
- Dra. Martha Inés Zuna Alcoba**  
Asesora Médica  
Fundación Nacional de Hemofilia Bolivia
- Victor Manuel Ponce Rojas**  
Presidente  
Fundación Nacional de Hemofilia Bolivia

**Informes Trinidad**  
Sra. Ariana Duran Dorado  
72293339  
Sra. Romy Dorado Cuellar  
72812144  
Secretaría Dirección  
Materno Infantil - 22418

## CONCLUSIONS

Thanks to the support of the WFH, the situation of patients with hemophilia in Bolivia has changed substantially in the number of patients registered and diagnosed. So far there is no governmental program to support these patients and to guarantee an adequate treatment.

