



The educational program Hemonline News

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Introduction and Objectives

In developing countries, patients with hemophilia and other bleeding disorders suffer from the lack of information about their disease and educational programs. In many of these countries there is not only need for therapies for hemophilia, but also patients do not have access to basic information, important for the management of daily problems, small hemorrhages and for learning behaviors that can help to prevent complications in the short and long-term. Furthermore, not all patients have access to the internet; for this reason we decided to create a magazine providing information that is sent to the national associations who request it

Results

Hemonline News is published every six months: 400 copies of each number are printed and sent by mail. The magazine is available in an electronic version, which can be also downloaded from our website (www.hemonline.it). Previous issues had articles from South, Central and North America, Europe, Africa and Asia. The magazine has been sent to 18 different countries.

Distribution of the Hemonline Magazine Worldwide



The Hemonline Project website



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Materials and Methods

The magazine, called Hemonline News, was founded in 2009 at the Hemophilia Center of Reggio Calabria thanks to the financial support of the Fondazione Paracelso; the other associations that collaborate in this project are: Hope and Life USA Foundation and the Associazione Emofilici di Reggio Calabria. The articles are written by hemophilia professionals, patients and their relatives: their contributions concerning the medical, pharmacological and social aspects with particular reference to comprehensive care; the patients and their relatives describe their experiences and their difficulties before receiving the correct diagnosis of bleeding disorder and the appropriate treatment. Articles are written in three languages: English, Spanish and Italian to facilitate the understanding in several countries

Conclusion

Our aim is to continue publishing for many years to provide educational support to local and national associations and therefore improve the information and consequently the quality of life of patients and their families. We also believe that the opportunity for patients and their families to tell their stories and express their feelings is a way to overcome social isolation and improve their self-esteem, especially in those societies where hemorrhagic diseases are still considered a source of shame.



N° 1 - June 2012



N° 2 - December 2012



N° 3 - June 2013



N° 4 - January 2014



N° 5 - December 2014



N° 6 - July 2015



N° 7 - February 2016

Authors Nationality	Authors for each country
Italy	9
Usa	3
Argentina	3
India	3
Philippines	1
Venezuela	1
Kenya	1
Yemen	1
Mexico	1
Chile	1
Bosnia Erzegovina	1
Cuba	1
England	1
Brazil	1
Malaysia	1
Total number of countries: 15	Total number of authors: 29



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Educational and Communication Models
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